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## Keywords

Psychiatric diagnosis; mental illness; children; young people; self; identity; qualitative; systematic review

## Introduction

Diagnosis is an important step in the everyday practice of mental healthcare, shaping clinical decisions regarding which treatment pathways and explanatory frameworks are appropriate. For the recipient, a psychiatric diagnosis can have profound practical, social and emotional implications (Jutel, 2009; Perkins et al., 2018). Diagnosis' effects may be particularly pronounced in childhood and adolescence, which are critical periods in the development of self and identity. To ensure diagnoses are communicated and managed in a way that optimally benefits mental health trajectories, understanding young people's first-hand experience of receiving and living with a diagnosis is paramount.

A diagnosis serves many functions for mental health service-users. At a practical level, a diagnosis can explain symptoms and facilitate access to resources, treatment and prognosis (Jutel, 2009). Research suggests ascribing appropriate diagnostic labels to psychological symptoms positively affects help-seeking and symptom management decisions (Wright et al., 2007). Service-users may further benefit from the 'common language' that diagnoses provide, which streamline communication between the different services and clinicians involved in their care. However, diagnoses can also have negative consequences for mental healthcare provision. Diagnoses may exclude people from certain services: for example, some child and adolescent mental health clinics do not accept clients with a primary diagnosis of Autistic Spectrum Disorder (ASD), and persons with a dual diagnosis of substance misuse and mental illness can fall between the cracks of different services' admission policies (Schulte and

24 Holland, 2008). Diagnoses with poor prognoses (such as personality disorders) can also lead  
25 to fatalism among service-providers and consequent restriction of treatment options (Nehls,  
26 1999; Newton-Howes et al., 2008; Ramon et al., 2001; Stalker et al., 2005).

27 These practical implications of psychiatric diagnosis must be considered alongside diagnoses'  
28 social and psychological effects, which are complex and diverse (Callard et al., 2013; Jutel,  
29 2015; Perkins et al., 2018). Particularly important are implications for the *self-concept*, defined  
30 as an individual's set of beliefs about herself/himself (Baumeister, 1999), and *social identity*,  
31 defined as the portion of the self-concept that derives from membership of social groups  
32 (Tajfel, 1981). Previous research suggests diagnostic classification can affect a person's self-  
33 concept and social identity in both positive and negative ways.

34 On the positive side, diagnosis can provide a sense of relief and self-understanding by implying  
35 symptoms result from a 'real', independent disease entity (Hayne, 2003; Horn et al., 2007). For  
36 people whose difficulties were previously dismissed as imaginary or self-inflicted, a diagnosis  
37 can be welcomed as validating their authenticity and severity (Dinos et al., 2004; Hayne, 2003;  
38 Punshon et al., 2009). Diagnosis can also protect self-image by apparently lessening personal  
39 culpability for undesirable behaviour and externalising the disorder from a person's 'true' self  
40 (Bilderbeck et al., 2014; Pitt et al., 2009). Within everyday social settings, disclosing a  
41 diagnosis can prompt more lenient treatment by facilitating access to the 'sick role' (Parsons,  
42 1975) that relieves a person of usual responsibilities. Furthermore, diagnosis can introduce  
43 service-users to a community of similar others and serve as a rallying-point around which  
44 people assemble to gain social support and advocate for services (Brownlow and O'Dell, 2006;  
45 McNamara and Parsons, 2016; Tan, 2018). Emerging research provides strong support for the  
46 importance of such social identity processes in promoting and maintaining mental health  
47 (Jetten et al., 2014). Diagnosis can thus have numerous positive implications for a person's  
48 social identity and personal self-concept.

49 However, a diagnosis also carries risks for self-concept and social relations. Psychiatric  
50 diagnosis can provoke grief and despair (Horn et al., 2007; Knight et al., 2003; Pitt et al., 2009;  
51 Ramon et al., 2001), particularly if it is associated with poor prognosis and treatment options.  
52 Some may struggle to reconcile a diagnosis with their previous self-image, and dislike feeling  
53 marked as ‘abnormal’ or ‘different’ (Hayne, 2003; Knight et al., 2003; Schulze and  
54 Angermeyer, 2003; Stalker et al., 2005). Another risk, often articulated under the rubric of  
55 labelling theory (Scheff, 1974), relates to the proposition that diagnoses function as self-  
56 fulfilling prophecies, i.e. that the disclosure of a diagnosis establishes expectations of certain  
57 behaviours, which influence how the person is treated and therefore makes those behaviours  
58 more likely. While some research has produced evidence supporting this proposal, particularly  
59 regarding diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in childhood (Harris  
60 et al., 1992; Sayal et al., 2010), recent longitudinal research finds no evidence prosocial  
61 behaviour worsened following a diagnosis of ASD (Russell et al., 2012).

62 A further concern is that disclosure of a diagnosis might exacerbate the stigma that symptoms  
63 of mental illness already attract (Ben-Zeev et al., 2010; Corrigan, 2007). People with direct  
64 experience of mental illness report that diagnostic disclosure leads to disadvantage in a range  
65 of interpersonal, employment, educational, health and social welfare settings (Dinos et al.,  
66 2004; Schulze and Angermeyer, 2003). Numerous studies have experimentally investigated the  
67 social effects of diagnosis by comparing people’s attitudes to hypothetical characters with and  
68 without a diagnostic label. This literature contains mixed effects, with some reporting a  
69 diagnostic label increases prejudice (Batzle et al., 2010; Harris et al., 1992; Ohan et al., 2013)  
70 and others that it does not (Jorm and Griffiths, 2008; Law et al., 2007; Thompson and Lefler,  
71 2016). Certain diagnostic labels are more stigmatising than others, e.g. young people with  
72 ADHD are perceived more negatively than those with depression (O’Driscoll et al., 2012).  
73 Schizophrenia, eating disorders and substance abuse are among the most stigmatised of

74 common mental illnesses (Angermeyer and Dietrich, 2006). Moreover, mental illness stigma  
75 is intersectional with socio-demographic categories: an eating disorder diagnosis, for example,  
76 is more stigmatising for males than females (Jones and Morgan, 2010).

77 Thus, receiving a psychiatric diagnosis can involve both positive and negative social,  
78 psychological and practical effects. This ambiguity can be reflected in service-users' attitudes  
79 towards receiving a diagnosis (Hayne, 2003; Pitt et al., 2009; Voorhees et al., 2005). For  
80 instance, a study of adaptation to a diagnosis of bipolar disorder found that people maintained  
81 ambivalent attitudes towards the diagnosis, with attitudes constantly in-flux across time,  
82 contextual circumstances, and symptomatic cycles (Inder et al., 2010). In real clinical contexts,  
83 individuals' responses to a given diagnosis are not determined purely by its scientific validity  
84 or clinical benefit; also important are the ways the diagnosis affects the person's self-  
85 understanding and social relationships.

86 The self and identity effects of diagnosis are likely particularly profound when the diagnosis is  
87 ascribed in early-life. Childhood is a time when identity is elastic and acutely sensitive to social  
88 experience (Bennett, 2011; Harter, 2012). Until recently, most empirical evidence regarding  
89 the psychological effects of childhood diagnoses reflected the perspective of parents (Ahern,  
90 2000; Osborne and Reed, 2008; Russell and Norwich, 2012; Singh, 2004) or people who  
91 receive a retrospective diagnosis of developmental disorder (e.g. ADHD) in adulthood  
92 (Punshon et al., 2009; Tan, 2018; Young et al., 2008). Recent years have seen increasing  
93 recognition of the need for mental health policy and practice to be informed by the perspective  
94 of young people themselves (LeFrancois, 2007; Sinclair, 2004). Researchers have  
95 demonstrated that, with appropriate attention to research design and ethical procedures,  
96 children with cognitive and behavioural difficulties are capable of productively engaging with  
97 the research process (Singh, 2007). This emerging literature has produced rich insights into the  
98 active ways young people negotiate psychiatric diagnoses and other aspects of the mental

99 health system (McNamara et al., 2017; Singh, 2011). Most of this evidence is qualitative in  
100 nature. The predominance of qualitative research is due to numerous factors. First, the relative  
101 youth of this field means much research is still exploratory, with insufficient evidence to inform  
102 hypothesis-driven quantitative studies. Second, recent policy emphasis on patient-centred care  
103 has prompted an upsurge of interest in lived experiences of service-users, which qualitative  
104 research is specifically suited to explore (Beresford, 2007; Davidson et al., 2008; Meyer, 2000).  
105 Finally, the pragmatic and ethical challenges of conducting research with children with  
106 cognitive, emotional and/or behavioural difficulties mean that standard methods such as  
107 questionnaires and experiments are often not appropriate or feasible: more dynamic, interactive  
108 data-elicitation methods are required (Singh, 2007; Whyte, 2005).

109 Previous literature reviews have confirmed the relevance of identity issues to the experience of  
110 mental illness (e.g. Boydell et al., 2010; Livingston and Boyd, 2010; Perkins et al., 2018).  
111 However, none have specifically focused on the first-hand experience of young people  
112 themselves. Additionally, most previous literature has focused on issues specific to a particular  
113 category of psychiatric diagnosis. Different diagnoses have widely divergent implications in  
114 terms of symptoms, treatment, and social attitudes, which undoubtedly mediate their effects on  
115 self-concept and social identity. However, the sociology of diagnosis has shown that useful  
116 insights can be gleaned by conceptualising diagnosis as a generic *process*, as well as specific  
117 category (Blaxter, 1978; Jutel, 2015). Comparisons of diagnosis' role in diverse medical fields  
118 reveal consistent patterns, for instance that diagnosis may induce 'biographical disruption'  
119 (Bury, 1982) or clinician-patient tensions (Jutel and Nettleton, 2011). Most youth psychiatric  
120 diagnoses share common problems establishing reliability and validity (Rutter, 2011; Timimi,  
121 2014), which have prompted a surge of interest in transdiagnostic approaches to research and  
122 treatment (McGorry and Nelson, 2016). Given that diagnosis marks a key point in most mental  
123 healthcare trajectories, a transdiagnostic approach is also appropriate for considering whether

124 this clinical practice has predictable implications for young people’s developing identity and  
125 self-concept. Both consistencies across and divergences between specific diagnoses’ effects  
126 are relevant to the ongoing debate about the role diagnosis should play in youth mental health  
127 contexts.

128 Research that enlightens young people’s first-hand experiences is an important source of  
129 insight into how young people’s self-concept and social identity are affected by receiving a  
130 psychiatric diagnosis. Understanding the range of possible effects, and the contexts in which  
131 they are most likely to occur, is relevant for many interest groups: clinicians deciding whether  
132 to offer a formal diagnosis, service-users considering whether to seek and accept a diagnosis,  
133 and families and teachers attempting to help young people adapt to a diagnostic classification.  
134 This review aims to collate, evaluate and synthesise the qualitative research that has explored  
135 how psychiatric diagnosis affects young people’s self-concept and social identity.

## 136 **Method**

### 137 **Design**

138 A systematic literature review was conducted, which followed the procedures stipulated by the  
139 PRISMA guidelines (Moher et al., 2009). Articles that met inclusion criteria were subjected to  
140 a quality assessment and thematic synthesis.

### 141 **Search strategy**

142 Keyword-searches were conducted in the following electronic databases: PsycINFO,  
143 PsycARTICLES, Academic Search Complete, Social Sciences Full Text, Embase, MEDLINE,  
144 PubMed Central, Science Citation Index Expanded, Social Sciences Citation Index, Arts &  
145 Humanities Citation Index.

146 As not all databases indexed entries using standardised searchable subject headings, the search  
147 strategy was keyword-based. Various combinations of keywords were trialled to identify a

148 sequence with an appropriate balance of sensitivity and specificity. The following keyword-  
149 string was judged to provide the optimal level of coverage, i.e. yielding a set of results that was  
150 comprehensive yet feasible for the research team to manually screen (<10,000). This keyword-  
151 string was adapted to suit the search functionalities of the different databases (e.g. different  
152 commands to indicate truncation).

153 a) [girl\* OR boy\* OR child\* OR youth\* OR "young person\*" OR "young people"  
154 OR teenag\* OR adolescent\*] in Title

155 AND

156 b) [qualitative OR interview\* OR "focus group\*" OR ethnograph\* OR  
157 "participant observation"] in All Fields

158 AND

159 c) [psychiatr\* OR psycholog\* OR mental] in All Fields

160 AND

161 d) [diagnos\*] in All Fields

162 AND

163 e) [self\* OR identit\*] in All Fields

164 Line (a) targeted the relevant research population. This line of keywords was restricted to the  
165 article title because searching for these terms in all fields produced an unmanageably large  
166 (>470,000) set of results. Line (b) targeted qualitative methodology. There are acknowledged  
167 challenges identifying qualitative articles through automated search filters, due to large  
168 differences in terminology usage among qualitative researchers (Grant, 2004; DeJean et al.,  
169 2016). As the review was interested in the first-hand perspective of young people, the search  
170 terms specified the most common data collection methods in qualitative research with human  
171 participants. The remaining lines restricted the search to articles discussing mental health,  
172 diagnosis, and self or identity.

173 **Inclusion and exclusion criteria**

174 Table 1 presents the inclusion and exclusion criteria that guided the selection of articles. The  
175 review was restricted to original qualitative studies where data was contributed by young  
176 people who held a recognised, DSM-listed psychiatric diagnosis. In accordance with the  
177 review's focus, results had to specifically address the question of how participants' diagnosis  
178 had affected their self-concept and/or social identity. For practical reasons relating to research  
179 resources, the review was restricted to articles published in peer-reviewed English-language  
180 journals. There were no restrictions regarding research location or publication date. The search  
181 was conducted in March 2017.

182 **Screening & eligibility assessment**

183 All references were imported into a reference manager software (Endnote) for screening. Initial  
184 screening of articles' eligibility was based on inspection of their title and abstract. Articles that  
185 did not meet inclusion criteria were excluded and the full texts of remaining articles (excepting  
186 one (Green, 1971) that proved impossible to access from existing databases or author requests)  
187 were acquired for eligibility assessment. To expand the review's comprehensiveness, the  
188 reference lists of included articles, along with those of any review/meta-analysis papers  
189 identified in the search process, were inspected for additional relevant papers.

190 Three reviewers independently screened a randomly-selected 10% ( $N=20$ ) of the articles that  
191 underwent full-text eligibility assessment to establish inter-reviewer reliability. Reviewers  
192 agreed on 95% of articles. Any ambiguities regarding articles' eligibility were resolved through  
193 team discussion, guided by the aim of ensuring maximal comprehensiveness of the review (i.e.  
194 erring on the side of inclusion rather than exclusion).

195 **Quality assessment**

196 There is little consensus regarding the most appropriate way of evaluating qualitative evidence  
197 within systematic reviews (Butler et al., 2016; Dixon-Woods et al., 2007; Hannes, 2011). In

198 accordance with increasingly common practice and the recommendations of the Cochrane  
199 Qualitative Research Methods Group (Cochrane Qualitative and Implementation Methods  
200 Group, 2013; Hannes, 2011), the current study included a structured critical appraisal stage.  
201 Given the heterogeneity of theoretical and methodological approaches involved, the aim was  
202 not to rank individual studies, but ensure that all met a minimum standard of research quality  
203 (Hannes, 2011). The instrument chosen was the commonly-used Critical Appraisal Skills  
204 Programme (CASP) Qualitative Checklist (Critical Appraisal Skills Programme, 2017). This  
205 evaluates articles along 10 dimensions of research quality. For this review, one dimension –  
206 adequate consideration of the researcher-participant relationship – was removed because  
207 different disciplinary norms make this dimension difficult to apply to a very multidisciplinary  
208 body of literature. On the remaining nine dimensions (clear statement of aims; qualitative  
209 method appropriate; design appropriate; recruitment strategy appropriate; data collection  
210 appropriate; ethical issues considered; data analysis rigorous; clear statement of findings; value  
211 of research), each article was scored to indicate whether the quality criterion was met (score =  
212 2), unclear (score = 1) or unmet (score = 0). All four authors contributed to the quality  
213 assessment, with each article independently assessed by two independent reviewers. Average  
214 inter-rater reliability using the CASP tool was 92.99%.

## 215 **Data extraction**

216 A data extraction tool was designed to record information about each study's:

- 217 • Region of data collection
- 218 • Stated aims
- 219 • Diagnoses and how they were determined
- 220 • Theoretical framework
- 221 • Design
- 222 • Sampling strategy

- 223 • Sample characteristics
- 224 • Analytic approach.

225 Appendix A displays the information extracted.

## 226 **Data analysis**

227 The key step in a qualitative systematic review is the synthesis of evidence from the included  
228 studies (Butler et al., 2016; Thomas and Harden, 2008). This review achieved this using  
229 thematic synthesis, an approach that applies principles of thematic analysis to reports of  
230 qualitative findings. Full texts of all articles were imported into ATLAS.ti. In accordance with  
231 Thomas and Harden (2008), the synthesis concentrated on material presented in the ‘Results’  
232 or ‘Findings’ sections of the articles. The results of each study were inspected and any text  
233 relating to the research question (the influence of diagnosis on self-concept and/or social  
234 identity) was highlighted. Through an iterative process, and in discussion with the research  
235 team, a coding frame was developed that captured the range of findings reported. Once the  
236 coding frame was finalised, all highlighted text was revisited and appropriate codes applied.  
237 Following Thomas and Harden’s (2008) procedure, basic-level codes were first organised into  
238 descriptive categories based on similarities in their content. ATLAS.ti’s analysis tools (e.g. co-  
239 occurrence analysis, sequencing) were utilised to explore relationships between codes, which  
240 were visually mapped using the Network function (see Appendix B) to construct higher-level  
241 analytic themes.

## 242 **Results**

### 243 **Results of literature search**

244 In total, the keyword-searches of the various databases returned 6,887 potential articles. Once  
245 duplicates were removed, 3,856 remained. After exclusion of articles that clearly did not meet  
246 inclusion criteria, 162 records remained. Full-text eligibility assessment found 27 met inclusion

247 criteria. Inspecting their reference lists revealed 36 further candidate articles, which underwent  
248 full-text eligibility assessment. Eleven were retained for the final sample.

249 These procedures produced a final sample of 38 articles. Figure 1's PRISMA Flow Diagram  
250 (Moher et al., 2009) presents the number of articles excluded at each stage. Table 2 and  
251 Appendix A list the studies included.

## 252 **\*Figure 1: PRISMA Flow Diagram\***

### 253 **Quality assessment scores**

254 Reviewers' total CASP scores for each article were averaged. Scores are displayed in Appendix  
255 A. Using thresholds adapted from Butler et al. (2016), most articles (78.9%;  $n=30$ ) were  
256 evaluated as high-quality (total score=16-18), seven articles moderate-quality (total score=13-  
257 15.5) and one low-quality (total score=10-13.5). None met the predetermined threshold for  
258 unacceptably low quality meriting exclusion from the review (total score<10).

### 259 **Thematic synthesis**

260 The thematic synthesis identified 11 analytic themes. These were organised into four  
261 overarching 'super-themes': *benefits for self-concept*, *risks for self-concept*, *benefits for social*  
262 *identity*, and *risks for social identity*. It should be noted that these thematic categories are  
263 deployed for parsimonious presentation of the results and do not imply that the data presented  
264 therein represent mutually exclusive phenomena: self-concept and social identity processes are  
265 intrinsically interconnected (Ellemers et al., 2002), and many diagnostic experiences had both  
266 positive and negative aspects. Themes are visually presented in Figure 2 and Appendix B and  
267 described below along with illustrative quotes from participants.

## 268 **\*Figure 2: Thematic structure\***

269 ***Benefits for self-concept***

270 **Self-understanding**

271 The explanatory value of a diagnosis, in providing a sense of self-insight, was evident in 14  
272 articles (Cheung et al., 2015; Cooper and Shea, 1998; Honkasilta et al., 2016; Huws and Jones,  
273 2008; Karterud et al., 2015; Kranke et al., 2011; Leavey, 2005; Lingam et al., 2013;  
274 McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2009; Singh, 2011;  
275 Skovlund, 2014; Wisdom and Green, 2004). Numerous young people defined their diagnosis  
276 as an explanation of their unusual behavioural traits (Cooper and Shea, 1998; Kranke et al.,  
277 2011).

278 *“I’ve never really fit in, I always felt different, and now I know why” (Kranke et al.,*  
279 *2011, p. 897)*

280 In these cases, diagnosis was presented as a revelation that afforded new means of making  
281 sense of the self. Some adolescents related being struck by a powerful sense of synchrony  
282 between the diagnosis and self.

283 *“Everything matched. In a way I got the answers” (Karterud et al., 2015, p. 110)*

284 In certain studies, participants’ diagnoses were assigned some time after the problematic  
285 behaviours first emerged. Participants who experienced delayed diagnosis stated their  
286 preference to have been diagnosed earlier (Cheung et al., 2015; Huws and Jones, 2008;  
287 Mogensen and Mason, 2015). A late diagnosis reframed biographical narratives, providing  
288 retrospective clarity on prior experiences. For instance, in three studies, a delayed diagnosis of  
289 ASD helped young people understand previously unexplained events, such as their struggles  
290 in school (Huws and Jones, 2008; McLaughlin and Rafferty, 2014; Mogensen and Mason,  
291 2015).

292           *Knowing what I have has helped me find out why I was always struggling at school and*  
293           *[...] getting into trouble” (Huws and Jones, 2008, p. 103)*

294 Valuation of diagnoses’ informative function was evident in some participants’ belief one  
295 should know as much about one’s diagnosis as possible. In seven articles, young people  
296 expressed a wish for more information or stated they had actively sought information about  
297 their disorder (Cheung et al., 2015; Floersch et al., 2009; Jones et al., 2015; Karterud et al.,  
298 2015; Kranke et al., 2010; Leavey, 2005; Wisdom and Green, 2004).

299           *“Let the children know more about this disorder...if I know what is happening to myself,*  
300           *the attitude, even the effect of the treatment will be different” (Cheung et al., 2015, p. 7)*

301 Some young people found the self-insight diagnosis afforded intrinsically meaningful, even in  
302 cases where the diagnosis did not indicate clear treatment options, such as psychogenic non-  
303 epileptic seizures (Karterud et al., 2015). For other participants, the insights diagnosis provided  
304 were valued for more pragmatic reasons, as a gateway to intervention and self-management.

305           *“I wanted to be labelled because I suddenly knew what I could do and I knew there was*  
306           *a way I could cope with that problem once it had been identified.” (Mogensen and*  
307           *Mason, 2015, p. 259)*

308 For instance, in one study, a diagnosis of ASD heightened young people’s self-awareness of  
309 problematic habits, which enabled them implement positive behaviour change (Mogensen and  
310 Mason, 2015). In another study of children with ADHD, the diagnosis was conflated with the  
311 introduction of pharmaceutical treatment (Cooper and Shea, 1998). Most participants construed  
312 access to treatment as a positive effect of diagnosis, although a minority portrayed intervention  
313 as intrusive (Avisar and Lavie-Ajayi, 2014; Kendall et al., 2003; Mogensen and Mason, 2015).

314 Thus, diagnosis facilitated a sense of self-understanding which was valued both intrinsically  
315 and as a door to self-management and clinical intervention.

### 316 **Self-legitimation**

317 Numerous articles alluded to the validating function of diagnosis (Karterud et al., 2015;  
318 Kendall et al., 2003; Mogensen and Mason, 2015; Wisdom and Green, 2004; Woodgate,  
319 2006). The diagnostic label, and the scientific authority it contained, legitimised the  
320 authenticity and severity of young people's experiences. The diagnosis reconstructed their  
321 struggles as a 'real disease', rather than variations on the normal spectrum of human emotion.

322 *"I think what would help is for people to realize that it is not just feeling down, it is*  
323 *actually an illness"* (Woodgate, 2006, p. 266)

324 For those who construed the diagnosis as legitimising their difficulties, the diagnosis offered a  
325 sense of relief or hope (Chavez et al., 2012; Cooper and Shea, 1998; Ingesson, 2007; Karterud  
326 et al., 2015; Leavey, 2005; Mogensen and Mason, 2015; Travell and Visser, 2006; Wisdom  
327 and Green, 2004). This partly related to perceived absolution from blame for undesirable  
328 behaviour. Several articles revealed young people using diagnoses of ADHD and ASD to  
329 mitigate responsibility for disobedience or peer conflict (Honkasilta et al., 2016; Singh, 2011;  
330 Singh et al., 2010; Skovlund, 2014).

331 *"Well, I realised that [...] whenever I got into trouble at school for talking and stuff, it*  
332 *wasn't my fault; it was because I had ADD [...] I couldn't help being distracted and that*  
333 *I wasn't concentrating properly."* (Cooper and Shea, 1998, p. 43)

334 This strategy for deflecting blame required ceding agency to the diagnosis. The disorder was  
335 positioned as an independent entity that compelled certain behaviours (Honkasilta et al., 2016;  
336 Kendall et al., 2003).

337           *“it’s something I can’t control, really. It’s like a part of you, like it’s hard... like even if*  
338           *you try to control it, it’s still like the better part of you is still in there, you know. So it’s*  
339           *not all the kid’s fault.” (Kendall et al., 2003, p. 122)*

340 Singh’s (2011) analysis of children with ADHD proposed that such renunciations of personal  
341 control were employed for strategic purposes in specific contextual circumstances, and did not  
342 necessarily indicate an omnipresent loss of agency. This accorded with numerous other studies.  
343 While some articles did contain quotes from young people indicating a sense of helplessness  
344 or passivity (e.g. *“It’s like a disease eating on you, you know, like you try to behave but it keeps*  
345 *on going on in your head to stop you behaving, and I always got in trouble for it.”* (Travell and  
346 Visser, 2006, p. 207)), other participants explicitly emphasised their control over their  
347 symptoms (Honkasilta et al., 2016; Kendall et al., 2003; Leavey, 2005; Skovlund, 2014;  
348 Wisdom and Green, 2004; Woodgate, 2006).

349           *“I own the illness; the illness doesn’t own me.” (Leavey, 2005, p. 118)*

350 Thus, attributing one’s behaviour to a diagnosis did not erode young people’s sense of agency.  
351 Rather, by legitimising the notion of a disease-entity, diagnosis allowed young people  
352 externalise their difficulties from their ‘core’ self and thereby protect their self-image.

### 353 **Self-enhancement**

354 Receiving a diagnosis did not necessarily engulf a person’s sense of self. In sixteen articles,  
355 young people articulated a self-concept that was clearly independent of their diagnosis  
356 (Floersch et al., 2009; Hallberg et al., 2010; Honkasilta et al., 2016; Huws and Jones, 2015;  
357 Jones, 2012; Karterud et al., 2015; Kendall et al., 2003; Kranke et al., 2011; Huws and Jones,  
358 2008; Huws and Jones, 2015; Moses, 2010; Skovlund, 2014; Tidefors and Strand, 2012; Travell  
359 and Visser, 2006; Wisdom and Green, 2004; Woodgate, 2006). The disorder was something  
360 they ‘had’ rather than something they ‘were’.

361           *“At the end of the day, people with autism are just the same as people who haven’t [got*  
362           *it], but they’ve just got something wrong with them, that’s it.” (Huws and Jones, 2015,*  
363           *p. 89)*

364 Neither did receiving a diagnosis necessarily impair a young person’s self-image. Thirteen  
365 articles presented young people expressing a distinctly positive self-concept (Daley and  
366 Weisner, 2003; Elkington et al., 2012; Honkasilta et al., 2016; Humphrey and Lewis, 2008;  
367 Huws and Jones, 2015; Jones et al., 2015; Krueger and Kendall, 2001; Lingam et al., 2015;  
368 McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Skovlund, 2014; Wisdom and  
369 Green, 2004; Woodgate, 2006). In some cases, they achieved this by focusing on positive  
370 personal traits that existed independently of the disorder, for instance *“my personality”* (Daley  
371 and Weisner, 2003; Lingam et al., 2013). More frequently, however, they reconstructed  
372 components of the disorder itself as positive (Daley and Weisner, 2003; Humphrey and Lewis,  
373 2008; Huws and Jones, 2015; Jones et al., 2015; Krueger and Kendall, 2001; McLaughlin and  
374 Rafferty, 2014; Mogensen and Mason, 2015; Skovlund, 2014). This perspective was most  
375 prominent for diagnoses of ASD. In two studies, participants explicitly oriented towards a  
376 characterisation of ASD as a *“gift”* and rejected its definition as *“disability”* (Daley and  
377 Weisner, 2003; Jones et al., 2015).

378           *“Most people with Asperger’s are very gifted. They learn things quick. They got good*  
379           *memories... They’re beyond extremely high functioning... And they’re mostly normal.*  
380           *[...] most of them are good looking.” (Daley and Weisner, 2003, p. 34)*

381 For disorders defined by negative emotional symptoms, such as depression, positive  
382 reconstrual of the symptoms themselves was less likely. However, in three studies of young  
383 people with depression, participants had nevertheless fashioned a self-affirming narrative  
384 around their diagnoses, by determining their experiences had ultimately strengthened their

385 character (Elkington et al., 2012; Wisdom and Green, 2004; Woodgate, 2006). Thus, diagnoses  
386 could be recruited as resources in maintaining a positive self-concept.

### 387 ***Risks for self-concept***

#### 388 **Self-threat**

389 Twelve articles presented evidence that a diagnosis can be experienced as a threat to one's self-  
390 concept (Elkington et al., 2012; Floersch et al., 2009; Hallberg et al., 2010; Huws and Jones,  
391 2008; Jones et al., 2015; Karterud et al., 2015; Kranke et al., 2010; Leavey, 2005; Mogensen  
392 and Mason, 2015; Travell and Visser, 2006; Wisdom and Green, 2004; Woodgate, 2006).  
393 Receiving a diagnosis could challenge a young person's previous self-image and force them to  
394 reconsider their identity. Some participants experienced this as a radical rupture of the self.

395 *“The safety of waking up and ‘knowing who you are’ which most people take for granted*  
396 *had suddenly vanished.” (Leavey, 2005, p. 115).*

397 On hearing their diagnosis, some participants failed to identify with it or recognise themselves  
398 in its formulation (Floersch et al., 2009; Huws and Jones, 2008; Karterud et al., 2015). Adapting  
399 to the diagnosis therefore involved assimilating new and potentially uncomfortable attributes  
400 into the self-concept (Hallberg et al., 2010; Jones et al., 2015). These attributes could be both  
401 previously unrecognised symptoms and disparaging judgements such as “*crazy*” (Kranke et al.,  
402 2010, p. 499). The very term “*mental illness*” was problematic for some (Karterud et al., 2015;  
403 Leavey, 2005). As numerous young people acknowledged, they themselves could hold  
404 negative stereotypes of people with psychological disorders (Elkington et al., 2012; Floersch  
405 et al., 2009; Humphrey and Lewis, 2008; Jones et al., 2015; Karterud et al., 2015; Kranke et  
406 al., 2011; Kranke et al., 2010; Leavey, 2005). This heightened the threat the diagnosis  
407 represented to their self-image.

408           *“Sometimes I don’t like myself because, having to go through a mental illness is such a*  
409           *bad thing that I label myself and look down on myself. Like the way I see other people*  
410           *who have illness, like this is a very stereotypical view, but [...] when I say the word*  
411           *‘mental illness’ it reminds me of bad, just bad in that... eww! Bad, who’d want that?”*  
412           *(Leavey, 2005, p. 114)*

413   These threatening connotations meant that initial responses to the diagnosis often involved  
414   shock, dejection or distress, present in 14 articles (Chavez et al., 2012; Floersch et al., 2009;  
415   Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Karterud et al., 2015;  
416   Kendall et al., 2003; Kranke et al., 2010; Leavey, 2005; McLaughlin and Rafferty, 2014;  
417   Mogensen and Mason, 2015; Pope, 2015; Travell and Visser, 2006; Wisdom and Green, 2004).  
418   One participant vocalised his first reaction to his diagnosis of Asperger’s disorder as *“Oh my*  
419   *God I’m a freak!”* (Humphrey and Lewis, 2008, p. 31). Dissonance with self-image sometimes  
420   prompted outright rejection of the diagnostic classification. Sixteen articles illustrated young  
421   people resisting or denying their diagnosis (Boughtwood and Halse, 2010; Cooper and Shea,  
422   1998; Daley and Weisner, 2003; Floersch et al., 2009; Huws and Jones, 2008; Jones, 2012;  
423   Karterud et al., 2015; Kendall et al., 2003; Kranke et al., 2011; Kranke et al., 2010; Leavey,  
424   2005; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2009; Pope, 2015;  
425   Travell and Visser, 2006). Other young people recounted having previously undergone stages  
426   of rejecting their diagnosis, although they now accepted it (Floersch et al., 2009; Kendall et al.,  
427   2003; Kranke et al., 2011; Kranke et al., 2010; Mogensen and Mason, 2015). The latter cases  
428   reflected the common finding that young people’s relationships with their diagnosis were  
429   unstable and changed over time (Elkington et al., 2012; Floersch et al., 2009; Hallberg et al.,  
430   2010; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Jones et al., 2015;  
431   Karterud et al., 2015; Kranke et al., 2010; Leavey, 2005; Pope, 2015). All cases of temporal

432 change in relationship with the diagnosis ran in the direction of increased acceptance of its  
433 validity.

434 *“At first I was like, ‘no. I can’t be bipolar.’ That’s just not me. I don’t want to be it and*  
435 *then when I started actually seeing what was really going on, I’m just like, oh my god, I*  
436 *can’t believe I just said that I wasn’t this, and now I am.” (Floersch et al., 2009, p. 166)*

437 While a minority ultimately came to view their diagnosis in emotionally neutral (Humphrey  
438 and Lewis, 2008; Kendall et al., 2003) or even positive (Daley and Weisner, 2003; Humphrey  
439 and Lewis, 2008; Lingam et al., 2013; Mogensen and Mason, 2015) terms, for most the  
440 diagnosis remained a distinctly negative attribute. They had felt they had no choice but to resign  
441 themselves to its presence in their lives (Daley and Weisner, 2003; Huws and Jones, 2008;  
442 Kendall et al., 2003; Krueger and Kendall, 2001).

443 *“I really find it annoying to have but it’s something that you’ve got to accept” (Huws*  
444 *and Jones, 2008, p. 104)*

445 In summary, the threat a diagnosis posed to self-image meant that initial resistance of it was  
446 common. Young people typically adapted to their diagnosis over time, but the self-  
447 reconstruction necessary meant this was often a difficult and protracted process.

#### 448 **Self-devaluation**

449 Assimilating a diagnosis could pose risks for young people’s self-esteem. Sixteen articles  
450 revealed young people expressing a distinctly negative self-image (Cheung et al., 2015; Cooper  
451 and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2013, 2012; Hallberg et al., 2010;  
452 Humphrey and Lewis, 2008; Ingesson, 2007; Jones, 2012; Karterud et al., 2015; Kranke et al.,  
453 2011; Krueger and Kendall, 2001; Leavey, 2005; Lingam et al., 2014; Singh et al., 2010;  
454 Travell and Visser, 2006). Young people variously viewed themselves as inferior (Cheung et  
455 al., 2015; Elkington et al., 2012; Elkington et al., 2013; Hallberg et al., 2010), inadequate

456 (Krueger and Kendall, 2001), damaged and incomplete (Cooper and Shea, 1998), flawed  
457 (Elkington et al., 2012), unintelligent (Daley and Weisner, 2003; Lingam et al., 2014; Travell  
458 and Visser, 2006), and undeserving of happiness (Elkington et al., 2013).

459 *“I’ve had pretty negative thoughts about myself and ADHD since I was little, especially*  
460 *when people are nagging me about things when I mess up. I try to do things right, but I*  
461 *can’t. I think it’s the way I’ll always be.” (Krueger and Kendall, 2001, p. 66)*

462 In most articles, it was unclear whether loss of self-worth was caused by the diagnosis itself,  
463 or the symptoms that presumably pre-dated it. However, the diagnosis certainly contributed to  
464 lowered self-worth for some young people by confirming that there was something  
465 fundamentally ‘wrong’ with them. The devaluing potential of diagnosis was more profound,  
466 the more an individual’s self was conflated with the diagnosis. For a minority of young people,  
467 their diagnosis represented the defining aspect of their self-concept (Kendall et al., 2003;  
468 Krueger and Kendall, 2001; Leavey, 2005; McLaughlin and Rafferty, 2014; Mogensen and  
469 Mason, 2015; Moses, 2009; Wisdom and Green, 2004). Such strong self-identification with a  
470 diagnosis mostly coincided with negative self-views, with the exception of some participants  
471 with ASD, whose diagnosis contributed to a self-image of uniqueness (Mogensen and Mason,  
472 2015).

473 Alongside young people’s sense their diagnosis marked them as flawed or deficient, studies  
474 also highlighted diagnoses’ pragmatic consequences for personal development. Young people  
475 in 11 studies stated that receiving the diagnosis had restricted their opportunities in education,  
476 career and relationships (Chavez et al., 2012; Hallberg et al., 2010; Huws and Jones, 2008,  
477 2015; Jones, 2012; Leavey, 2005; McLaughlin and Rafferty, 2014; Moses, 2010; Singh et al.,  
478 2010; Travell and Visser, 2006; Woodgate, 2006). For instance, adolescents with ADHD  
479 worried disclosing their diagnosis would invite discrimination from prospective employers

480 (Hallberg et al., 2010). Young people positioned their diagnosis as responsible for unwanted  
481 education placements (Jones, 2012; Moses, 2012), inability to pursue further education or  
482 desired career trajectories (Huws and Jones, 2008, 2015; Leavey, 2005), educational  
483 underperformance (Leavey, 2005; McLaughlin and Rafferty, 2014; Skovlund, 2014), unfair  
484 treatment from teachers (Moses, 2010; Singh et al., 2010) and peer discord (McLaughlin and  
485 Rafferty, 2014; Singh et al., 2010). These attributions caused significant resentment of the  
486 diagnosis – although again, it was often difficult to disentangle the degree to which young  
487 people blamed the diagnostic label itself, versus the disorder’s symptoms. For some young  
488 people, the diagnosis’ perceived curtailment of opportunities fostered trepidation about their  
489 future (Chavez et al., 2012; Hallberg et al., 2010; Huws and Jones, 2015, 2008; Ingesson, 2007;  
490 Kranke et al., 2011, 2010; Krueger and Kendall, 2001; Leavey, 2005; Lingam et al., 2014;  
491 Travell and Visser, 2006). Others adopted a pragmatic stance, arguing that one must simply  
492 “*accept it and your limitations*” (Woodgate, 2006, p. 265). A recurrent finding was that after  
493 the diagnosis, young people’s expectations and aspirations for the future were revised  
494 downward.

495           *“Like, my goals used to be set really high, get high marks, go to university. Now it’s just*  
496           *graduate high school and maybe go to college.” (Leavey, 2005, p. 118).*

497 Thus, accepting a psychiatric diagnosis could lead to anxiety about future prospects and  
498 realignment to less ambitious career and educational plans.

## 499 ***Benefits for social identity***

### 500 **Social identification**

501 Thirteen articles presented evidence that young people derived a sense of social identity from  
502 their diagnosis (Brady, 2014; Daley and Weisner, 2003; Elkington et al., 2012; Floersch et al.,  
503 2009; Jones et al., 2015; Kranke et al., 2010; Leavey, 2005; Lingam et al., 2014; McLaughlin

504 and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2010; Skovlund, 2014; Wisdom and  
505 Green, 2004). Numerous young people described bonds with peers who held similar diagnoses.  
506 These were sometimes pre-existing friends who happened to also experience mental health  
507 problems (Floersch et al., 2009; Moses, 2010), sometimes other users of relevant services  
508 (Leavey, 2005; Lingam et al., 2013), and sometimes prior acquaintances which became closer  
509 following the discovery of a shared diagnosis (Brady, 2014; McLaughlin and Rafferty, 2014).  
510 Family members who experienced similar difficulties also offered social understanding and  
511 acceptance (Moses, 2010).

512 Relationships with similar others had a special quality that was valued above friendships with  
513 ‘normal’ peers (Leavey, 2005). These relationships held a transparency lacking from other  
514 friendships, as young people disclosed more personal information to others with shared  
515 experience (Elkington et al., 2012). These friendships were an outlet for sharing mental health-  
516 related experience and advice – even, on occasion, medication (Brady, 2014). Young people  
517 who attended organised peer support groups appreciated the opportunity they presented to  
518 forge these connections, which were valued both intrinsically and as resources for mental  
519 health (Leavey, 2005; Lingam et al., 2013). Numerous young people alluded to a prior  
520 isolation, that was resolved through meeting others in similar situations (Jones et al., 2015;  
521 Kranke et al., 2010).

522 *“I mean it's easier to understand like other people have this condition. You're going*  
523 *through it. I'm not the only one. Other people are like me. I mean it just so I don't feel*  
524 *isolated.” (Kranke et al., 2010, p. 500)*

525 The collective identity attached to their diagnosis was reflected in pronouns such as “we” and  
526 “us”, indicating identification with others in one’s diagnostic category. Face-to-face contact  
527 was not the only means of developing this solidarity: online communication and simply reading

528 about others with a diagnosis served similar functions (Elkington et al., 2012; Jones et al., 2015;  
529 Mogensen and Mason, 2015). Contact with others who shared the diagnosis afforded a much-  
530 wanted sense of belonging and validation (Jones et al., 2015).

531 *“I think of a lone jelly bean all by myself. No friends, until he realizes, I’m not alone; I’m*  
532 *not the only jelly bean. There are jelly beans just like me, I’m not alone” (Jones et al.,*  
533 *2015, p. 1499)*

534 Thus, one function of a diagnosis was to alert young people that there were others ‘like them’,  
535 and many actively sought to cultivate relationships with these similar others.

### 536 **Social acceptance**

537 Diagnoses could have positive implications for young people’s social relationships generally.  
538 In eight articles, young people reported their interpersonal relationships had improved  
539 following their diagnosis (Elkington et al., 2012; Hallberg et al., 2010; Humphrey and Lewis,  
540 2008; Kranke et al., 2010; Leavey, 2005; Mogensen and Mason, 2015; Singh, 2011; Singh et  
541 al., 2010).

542 *“After I got sick, people were so nice, they never gets [sic] angry at me” (Leavey, 2005,*  
543 *p. 116)*

544 Teachers could become more tolerant after learning about a child’s diagnosis (Honkasilta et  
545 al., 2016; Lingam et al., 2013; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015;  
546 Moses, 2010; Singh, 2011). Some young people reported that their relationships with their  
547 parents had improved since their diagnosis, making interactions more accepting and open  
548 (Elkington et al., 2012; Leavey, 2005). Since many only selectively disclosed their diagnosis  
549 outside the home, the family often represented a comfortable setting where one’s diagnosis was  
550 known and understood (Hallberg et al., 2010). Reluctance to disclose the diagnosis to peers  
551 was driven largely by anticipation that friends would treat one differently as a result. However,

552 these expectations were not always realised: some participants reported that revealing their  
553 diagnosis to peers had led to increased understanding (Elkington et al., 2012; Humphrey and  
554 Lewis, 2008), while others were gratified by their friends' indifference to their diagnosed status  
555 (Kranke et al., 2010; Moses, 2010).

556 A further way diagnosis could smooth social relations was its potential deployment as a weapon  
557 against unkind treatment. Some young people opted to identify themselves using the official  
558 diagnostic term as a preferred alternative to derogatory slang for mental illness (Cooper and  
559 Shea, 1998). Young people could also harness the fear associated with mental illness to their  
560 benefit: three articles identified young people who deployed the diagnosis to offset the threat  
561 of bullying (Huws and Jones, 2008; Singh et al., 2010; Singh, 2011).

562 *"I have like told people I got ADHD cos it makes them leave you alone. They're nervous*  
563 *that you might really hurt them if you get wound up."* (Singh, 2011, p. 894)

564 Numerous young people recounted experiences of positive discrimination or 'special  
565 treatment' resulting from their diagnosis (Daley and Weisner, 2003; Elkington et al., 2012;  
566 Humphrey and Lewis, 2008; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015;  
567 Moses, 2010; Singh, 2011; Woodgate, 2006). Diagnoses alerted others to young people's  
568 challenges in certain domains, prompting more benevolent attitudes and practical assistance.  
569 However, although participants acknowledged this was kindly meant, they were often  
570 uncomfortable with these experiences, which contradicted their desire to retain a sense of  
571 normality (Daley and Weisner, 2003; Elkington et al., 2012; McLaughlin and Rafferty, 2014).  
572 Intensive monitoring or overprotective responses from parents were not appreciated (Leavey,  
573 2005; Moses, 2010). Young people also disliked when teachers were overly attentive or lenient  
574 due to their diagnosis, thereby drawing attention to their difference from their peers. This  
575 rejection of preferential treatment or "*extra attention*" (Humphrey and Lewis, 2008, p. 38)

576 sometimes extended to learning supports to which they were entitled, such as special needs  
577 assistants.

578 *“I don’t want people to treat me differently because people with Aspergers [get treated]*  
579 *differently to everybody else and I don’t like it at all. I don’t like this sort of thing you*  
580 *know I don’t like people coming to my lessons. [...] If they were following me then the*  
581 *other students know that there’s something different about me and I don’t like it at all.*  
582 *[...] Often it’s like – I don’t really like the extra attention.” (Humphrey and Lewis, 2008,*  
583 *p. 38)*

584 Thus, young people often reported that their diagnosis had fostered a more tolerant,  
585 understanding social environment. However, this was qualified by discomfort when disclosure  
586 of a diagnosis led other people to dramatically change their behaviour towards them (Moses,  
587 2010). Most young people wished to preserve a continuity of identity pre- and post-diagnosis,  
588 and so it was important that others acknowledge their essential identity was unaffected by the  
589 diagnosis (Karterud et al., 2015; Woodgate, 2006).

### 590 **Social comparison**

591 Holding a diagnosis afforded young people a classification unique among their peers, which  
592 left many in some confusion regarding their social positioning. The literature illuminated the  
593 social cognitive processes by which young people sought to orient themselves in their social  
594 milieu. Twelve articles observed young people spontaneously engaging in social comparison,  
595 i.e. evaluating their own social status in relation to others (Cooper and Shea, 1998; Daley and  
596 Weisner, 2003; Elkington et al., 2012; Huws and Jones, 2015; Jones, 2012; Jones et al., 2015;  
597 Kendall et al., 2003; McCann et al., 2012; McLaughlin and Rafferty, 2014; Moses, 2009; Singh  
598 et al., 2010; Skovlund, 2014). In almost all cases, the direction of comparison was downward,

599 with young people enhancing their own self-esteem by comparing themselves positively to  
600 more impaired others.

601 The spectrum formulation of ASD provided a particularly amenable platform for these social  
602 comparison processes (Huws and Jones, 2015; Jones et al., 2015). The distinction between  
603 ‘Asperger’s’ and ‘autism’ was important to some participants (Huws and Jones, 2015;  
604 McLaughlin and Rafferty, 2014). In one ASD study, every participant alluded to variation in  
605 the severity of autism symptoms, and all defined their own symptoms as mild relative to  
606 individuals who were “*really, really autistic*” or who have “*got it very bad*” (Huws and Jones,  
607 2015, p. 87).

608 *“I’m not as bad as the others here.” (Huws and Jones, 2015, p. 87)*

609 Such patterns were also visible for other diagnoses. Children with a diagnosis of ADD  
610 distinguished themselves from a diagnosis of ADHD, which they saw as more extreme (Cooper  
611 and Shea, 1998). Adolescents with intellectual disabilities differentiated between “*normal*” and  
612 “*disabled*” children, aligning themselves with the former (Daley and Weisner, 2003), and  
613 distinguished between “*just*” having a mental disability and having a “*proper*” (i.e. physical)  
614 disability (Huws and Jones, 2015; Jones et al., 2015). Young people whose difference from  
615 typically developing peers was materialised in their separation into special classrooms  
616 dissociated themselves from their more impaired classmates (Jones, 2012). Young people with  
617 emotional disorders minimised their own difficulties by observing that others had more severe  
618 symptoms (McCann et al., 2012; Moses, 2009). One study observed that young people  
619 distanced themselves from the category of “*crazy*” by locating it with more extreme cases they  
620 encountered in clinical settings or the media (Elkington et al., 2013). However, this strategy  
621 was restricted to individuals with nonpsychotic disorders; youth with psychotic disorders did  
622 not engage in this form of social comparison (Elkington et al., 2013).

623 In only one case – an adolescent with multiple comorbidities in Moses (2009) – was upward  
624 social comparison (i.e. comparison with a higher-functioning person) employed to emphasise  
625 the severity of one’s own difficulties. All other cases of social comparison were directed  
626 downward to more impaired others, which made oneself appear relatively robust in  
627 comparison. Just as young people distanced themselves from more severely impaired  
628 individuals, they also took pains to emphasise their similarity to “normal” peers (Avisar and  
629 Lavie-Ajayi, 2014; Daley and Weisner, 2003; Elkington et al., 2012; Humphrey and Lewis,  
630 2008; Huws and Jones, 2015; Ingesson, 2007; Mongensen and Mason, 2015; Moses, 2010;  
631 Singh, 2011; Wisdom and Green, 2004).

632 *“I am normal. I do bleed red blood. I do know how to read. I know how to do everything*  
633 *the kids do.” (Daley and Weisner, 2003, p. 31)*

634 Older adolescents were particularly keen to emphasise that they were no different from their  
635 friends or siblings (Moses, 2010). Participants with mood disorders achieved this normalisation  
636 by emphasising the ubiquity of the experience of emotional distress (Elkington et al., 2012) or  
637 observing parallels between their own difficulties and those of their peers (Wisdom and Green,  
638 2004).

639 Thus, a psychiatric diagnosis should not be equated with an inevitable designation of social  
640 deviance or inferiority: young people actively engaged in creative social cognitive strategies  
641 for preserving their sense of worth. They organised their own and others’ diagnoses into  
642 hierarchies that set themselves in a relatively advantaged position. It should be noted that these  
643 social comparison processes are not optimal at a systemic level, as they can undermine  
644 solidarity and fuel stigmatisation of the most impaired young people. Their benefits lie purely  
645 at an individual level: diagnoses afford young people tangible markers to identify targets  
646 relative to whom they can feel advantaged.

647 ***Risks for social identity***

648 **Social alienation**

649 In eighteen articles, young people expressed acute awareness of their difference from their  
650 peers (Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2012; Hallberg et  
651 al., 2010; Humphrey and Lewis, 2008; Huws and Jones, 2015; Ingesson, 2007; Jones, 2012;  
652 Jones et al., 2015; Kendall et al., 2003; Kranke et al., 2011, 2010; Leavey, 2005; McCann et  
653 al., 2012; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Travell and Visser,  
654 2006; Woodgate, 2006). In some cases, young people had been aware of their atypicality prior  
655 to the diagnosis, and the diagnosis had simply helped them make sense of it (Mogensen and  
656 Mason, 2015). In other cases, awareness of difference was prompted by the diagnosis itself:  
657 for instance, one study suggested that young people’s sense of deviance arose only after they  
658 received an ADHD diagnosis (Hallberg et al., 2010). In both scenarios, the diagnostic label  
659 was critical in alerting *other* people to the young person’s deviance, which was generally  
660 experienced as unpleasant (Elkington et al., 2012; Humphrey and Lewis, 2008; Jones et al.,  
661 2015).

662 *“I kind of just feel, I feel like I am just marked. Like people just have, some people just*  
663 *kind of treat me different, and I don’t want to be treated different, I just wanted to be*  
664 *treated how I was” (Jones et al., 2015, p. 1498)*

665 As outlined above, some young people fostered a positive self-concept by emphasising their  
666 unique talents (Jones et al., 2015; Mogensen and Mason, 2015). However, when young people  
667 explicitly defined themselves as “*different*” from peers, this was almost exclusively presented  
668 as a negative attribute (Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al.,  
669 2012; Hallberg et al., 2010; Humphrey and Lewis, 2008; Huws and Jones, 2015; Kendall et al.,  
670 2003; Kranke et al., 2011; Lingam et al., 2013; Travell and Visser, 2006). The status of

671 “*different*” was often conflated with “*abnormal*” (Humphrey and Lewis, 2008; Kranke et al.,  
672 2011), with deviations from normality described using terminology such as “*weird*”, “*odd*” or  
673 “*strange*”. Perceiving oneself as different from others was therefore bound up with a  
674 devaluation of one’s relative worth (Cooper and Shea, 1998; Huws and Jones, 2015; Ingesson,  
675 2007).

676 *“Sometimes, when I was little, I thought that I was an alien [...] I thought that I was*  
677 *different from the others, and I didn't really care about me because - well like, I cared*  
678 *about me – but I didn't care about me much, because I just thought that I was really*  
679 *different. And that I wasn't the type of person I should be.” (Cooper and Shea, 1998, p.*  
680 *42)*

681 Young people believed their difference was evident to others and found it difficult to “*fit in*”  
682 (Mogensen and Mason, 2015, p. 259) with their peers (McLaughlin and Rafferty, 2014). The  
683 effort involved in trying to appear “*as everyone else*” (Hallberg et al., 2010, p. 215) was  
684 burdensome (Hallberg et al., 2010; Humphrey and Lewis, 2008). Several young people  
685 expressed a wish for a magical intervention that would “*make me normal*” (Humphrey and  
686 Lewis, 2008, p. 31) (Hallberg et al., 2010; Humphrey and Lewis, 2008; Leavey, 2005; McCann  
687 et al., 2012).

688 *“I wish that this diagnose [sic] vanished, so I became normal” (Hallberg et al., 2010, p.*  
689 *215)*

690 As well as the intrinsic dislike participants felt towards their “*different*” status, difference had  
691 the pragmatic effect of contributing to social isolation (Kranke et al., 2011; McLaughlin and  
692 Rafferty, 2014; Mogensen and Mason, 2015). In three studies (Daley and Weisner, 2003;  
693 Elkington et al., 2012; Woodgate, 2006), young people defined themselves as “*outcasts*”.

694 *“I don't like being classified. Like I'm not classified as regular. I'm classified as outcast.*  
695 *[...] outcasts don't have a life, outcasts are dogs in other people's eyes.” (Daley and*  
696 *Weisner, 2003, p. 38)*

697 Young people directly attributed social exclusion (Hallberg et al., 2010; Jones, 2012) or  
698 victimisation (Humphrey and Lewis, 2008) to being recognised as different.

699 *“I just don't feel normal... me being different may be one of the reasons I ain't got no*  
700 *friends or something” (Kranke et al., 2011, p. 897)*

701 In 12 articles, young people reported that their interpersonal relationships had suffered due to  
702 their diagnosis (Chavez et al., 2012; Elkington et al., 2012, 2013; Hallberg et al., 2010;  
703 Ingesson, 2007; Jones, 2012; Kranke et al., 2010; Leavey, 2005; McCann et al., 2012;  
704 McLaughlin and Rafferty, 2014; Moses, 2010; Singh, 2011). For some, the diagnosis had made  
705 them a target for ridicule and bullying (Chavez et al., 2012; Elkington et al., 2012; Ingesson,  
706 2007; Singh, 2011). Young people described rejection and abandonment from previous friends  
707 (Elkington et al., 2012; Leavey, 2005; Moses, 2010) and blamed the diagnosis for the absence  
708 of friends they would otherwise have had (Kranke et al., 2011; McLaughlin and Rafferty,  
709 2014). Among older participants, a sense of isolation was heightened by a belief that the  
710 diagnosis impeded the formation of fulfilling romantic relationships.

711 *“I wish I could get rid of my diagnosis, it holds me back in relation to girls” (Hallberg et*  
712 *al., 2010, p. 215)*

713 Adolescents believed the diagnosis would lead prospective partners to expect they were  
714 unreliable or burdensome (Elkington et al., 2013; Hallberg et al., 2010; Leavey, 2005). In one  
715 study, this sense of low desirability as a romantic partner led some young people to accept  
716 abusive or unfulfilling relationships (Elkington et al., 2013)

717 Thus, many young people felt their social connections had been impoverished by their  
718 diagnosis, because it drew others' attention to their difference from the norm.

### 719 **Social invalidation**

720 In 11 articles, young people complained of low awareness of mental illness within their social  
721 circle and society generally (Elkington et al., 2012; Honkasilta et al., 2016; Humphrey and  
722 Lewis, 2008; Jones et al., 2015; Karterud et al., 2015; Kranke et al., 2011, 2010; Leavey, 2005;  
723 Lingam et al., 2014; Mogensen and Mason, 2015; Singh et al., 2010). They expressed a wish  
724 for greater public education about their disorders (Humphrey and Lewis, 2008; Jones et al.,  
725 2015; Mogensen and Mason, 2015; Singh et al., 2010).

726 *“It is the teachers [that] are rubbish – they know about their subject but they know*  
727 *nothing about us with Asperger’s syndrome but then why should they – they’ve never*  
728 *been told – they’re not specially trained to deal with people with special needs”*  
729 *(Humphrey and Lewis, 2008, p. 39)*

730 Young people bemoaned misunderstandings of their diagnosis they encountered in others.  
731 These misunderstandings could arise even within the family home, with some young people  
732 indicating their parents did not correctly understand the implications of their diagnosis (Kranke  
733 et al., 2011, 2010). Young people felt that following their diagnosis, they were viewed as less  
734 capable and competent than they had previously been. They were no longer trusted with the  
735 level of responsibility they had previously been afforded (Elkington et al., 2012; Leavey, 2005;  
736 Moses, 2010).

737 *“[They] treat me differently since I got diagnosed with an illness. I think*  
738 *subconsciously, yeah. They don’t realize it either, because they’re overprotective. They*  
739 *want me home by a certain time” (Leavey, 2005, p. 116)*

740 As discussed above, young people were often uncomfortable receiving ‘special help’ at school  
741 or home, especially if this was seen as motivated by pity (Moses, 2010). Some also suggested  
742 overly benevolent treatment denied young people agency and the opportunity to challenge  
743 themselves (Daley and Weisner, 2003).

744 *“I mean [the other teens] really liked me and helped me, but they treated me as if I was*  
745 *helpless. And they treated me as if I didn't know how to do anything. Like, greeeaaat. So,*  
746 *at times it was kind of fun but at other times it was kind of boring, because, you know, I*  
747 *can do things, I'm not dumb. I can figure it out. And the only way I'm going to get*  
748 *independent is by trying.” (Daley and Weisner, 2003, p. 33)*

749 Some participants suggested the diagnosis had involved a loss of identity: in other people’s  
750 eyes, they became a unidimensional being defined solely by their diagnosis (Elkington et al.,  
751 2012). Equally problematic as others investing too much importance in the diagnosis, were  
752 instances of people refusing to accept the diagnosis as a legitimate medical condition. A  
753 minority of young people related experiences of such resistance to their diagnosis from school  
754 authorities (Brady, 2014; Singh, 2011), family (Elkington et al., 2012; Moses, 2010), healthcare  
755 providers (Karterud et al., 2015) and friends (Moses, 2010).

756 *“they think I’m just doing it for attention” (Moses, 2010, p. 988)*

757 Others’ refusal to accept one’s diagnosis as valid was experienced as distressing, particularly  
758 for young people who invested deeply in the diagnosis in articulating their identity.

### 759 **Social stigmatisation**

760 Direct experience of stigma arose in 23 of the papers reviewed (Avisar and Lavie-Ajayi, 2014;  
761 Chavez et al., 2012; Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2013,  
762 2012; Hallberg et al., 2010; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson,

763 2007; Jones, 2012; Jones et al., 2015; Kendall et al., 2003; Kranke et al., 2011, 2010; Leavey,  
764 2005; McCann et al., 2012; Mogensen and Mason, 2015; Moses, 2010; Singh, 2011; Singh et  
765 al., 2010; Travell and Visser, 2006; Woodgate, 2006). The most commonly discussed source  
766 of stigma, present in 11 articles, was the young person's peer-group (Daley and Weisner, 2003;  
767 Elkington et al., 2012; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007;  
768 Jones, 2012; Kendall et al., 2003; Kranke et al., 2011, 2010; McCann et al., 2012; Singh, 2011).  
769 In seven articles, most involving developmental disorders, young people related experiences  
770 of bullying from classmates or friends (Daley and Weisner, 2003; Hallberg et al., 2010;  
771 Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Kranke et al., 2010;  
772 Singh, 2011).

773 *“Persecution! Being beaten up, assaulted. You don't get much worse than that. Assault*  
774 *is pretty, pretty bad” (Daley and Weisner, 2003, p. 38)*

775 In several cases the bullying was directly attributed to the disclosure of a diagnosis, which  
776 made people a target for victimisation.

777 *“Because I told [peers] about my ADHD, they thought if they could wind me up I'd get*  
778 *really upset and they love to do that” (Singh, 2011, p. 893)*

779 The second most frequently mentioned sources of stigma, manifesting in six articles  
780 encompassing a range of diagnoses, were school authorities (Cooper and Shea, 1998; Elkington  
781 et al., 2012; Humphrey and Lewis, 2008; Kranke et al., 2011; Moses, 2010; Singh et al., 2010).  
782 Numerous young people saw their diagnosis as negatively impacting their educational  
783 experience due to the bad reputation it afforded them (Singh et al., 2010). Specific complaints  
784 ranged from placement in inappropriate classroom contexts, undemanding work, intensive  
785 monitoring, false accusations of trouble-making and verbal abuse from teachers.

786           *“He (teacher) was like... we're going' push you down and shove that medication down*  
787           *your throat, (if) you keep on acting crazy” (Kranke et al., 2010, p. 501)*

788    In three studies, young people positioned their family as a source of stigma (Elkington et al.,  
789    2012; Kranke et al., 2010; Moses, 2010). In these families, the diagnosis was seen as shameful  
790    and relatives worried they would be contaminated by their association with the young person.  
791    Extended family might distance themselves from the diagnosed individual (Moses, 2010),  
792    while immediate family might encourage secrecy about the diagnosis (Elkington et al., 2012).

793           *“My dad asks ‘Why do I have to talk to a stranger about my problems?’” (Elkington et*  
794           *al., 2012, p. 300)*

795    The media was faulted for propagating stigmatising representations of mental illness in three  
796    studies (Elkington et al., 2012; Kranke et al., 2011; Leavey, 2005).

797           *“usually when you see images of a mental institution on TV, it’s perceived as a place*  
798           *where dangerous and violent people are kept” (Elkington et al., 2012, p. 299)*

799    Less commonly mentioned outlets for stigma were interactions with health professionals  
800    (Avisar and Lavie-Ajayi, 2014; Mogensen and Mason, 2015), intimate relationships (Elkington  
801    et al., 2013) and the workplace (Hallberg et al., 2010).

802    Participants attributed their personal experience of social rejection to negative cultural  
803    representations of their diagnosis (Elkington et al., 2012). The diagnostic label was blamed for  
804    encouraging preconceptions about a person that may not align with their actual attributes: as  
805    one participant put it, *“the problem with having a label is that people always prejudge you”*  
806    (Huws and Jones, 2008, p. 103). These prejudgements were shaped by common stereotypes of  
807    mental illness, of which young people were aware and resentful. Young people specifically  
808    criticised the association of various psychiatric diagnoses with attributes of aggression and

809 violence (Elkington et al., 2012; Singh, 2011), unreliability (Elkington et al., 2013), volatility  
810 (Elkington et al., 2013; Moses, 2010), low intelligence (Kendall et al., 2003; Singh et al., 2010),  
811 poor social skills (Mogensen and Mason, 2015), incompetence (Elkington et al., 2012; Leavey,  
812 2005; Mogensen and Mason, 2015; Moses, 2010), and disobedience (Moses, 2010; Singh,  
813 2011). These stereotypes were experienced as oppressive and gave rise to feelings of being  
814 radically misunderstood. Young people particularly objected to stereotypes that inflated the  
815 severity of their presumed disturbance.

816 *“They think you’re a murderer” (Elkington et al., 2012, p. 298)*

817 Young people strongly and repeatedly objected to derogatory terms for mental illness. Specific  
818 words mentioned were “*retard*”, “*weirdo*”, “*crazy*”, “*psycho*”, “*nuts*”, “*cuckoo*”, “*zombie*”,  
819 “*freak*” and “*loser*”. Young people exposed to such language felt mischaracterised and  
820 demeaned, and positioned this language as a risk factor for poor self-worth.

821 *“Crazy. Psycho. Nuts. 'Cause that's what I heard from everyone else. My mom would be*  
822 *like, 'You're psycho. You're crazy.' My brother would be like, 'You're freakin' psychotic.*  
823 *You're a nut case,' so I'd just, you know, those were my words for what I had.” (Kranke*  
824 *et al., 2010, p. 500)*

825 Young people’s responses to stigma could be classified into three main forms: *stigma*  
826 *internalisation*, *stigma resistance*, and *stigma avoidance*. The latter strategy was visible in 18  
827 articles, where young people sought to conceal or selectively disclose their diagnosis (Cooper  
828 and Shea, 1998; Elkington et al., 2012, 2013; Hallberg et al., 2010; Honkasilta et al., 2016;  
829 Humphrey and Lewis, 2008; Ingesson, 2007; Kendall et al., 2003; Kranke et al., 2010, 2011;  
830 Leavey, 2005; Lingam et al., 2014; McCann et al., 2012; Mogensen and Mason, 2015; Moses,  
831 2010; Singh et al., 2010; Singh, 2011; Wisdom and Green, 2004). Some were emphatic they

832 did not want other people to know of their diagnosis, due to the differential treatment they  
833 anticipated (Humphrey and Lewis, 2008).

834 *“I’d prefer they didn’t know because everyone treats me differently and I don’t like being*  
835 *treated differently.” (Humphrey and Lewis, 2008, p. 31)*

836 At times, concealing one’s diagnosis simply involved refraining from volunteering the  
837 information in social interactions. At other times, more active deception strategies were  
838 necessary, for instance lying about reasons for hospitalisations (Elkington et al., 2012), hiding  
839 medication (Kranke et al., 2010, 2011), or curtailing the development of relationships ((Kranke  
840 et al., 2010; McCann et al., 2012).

841 Eighteen articles contained evidence of direct resistance of stigma (Avisar and Lavie-Ajayi,  
842 2014; Daley and Weisner, 2003; Elkington et al., 2012; Floersch et al., 2009; Honkasilta et al.,  
843 2016; Huws and Jones, 2015; Jones et al., 2015; Kendall et al., 2003; Kranke et al., 2010, 2011;  
844 Krueger and Kendall, 2001; Leavey, 2005; McLaughlin and Rafferty, 2014; Mogensen and  
845 Mason, 2015; Moses, 2009; Moses, 2010; Pope, 2015; Wisdom and Green, 2004). Stigma  
846 resistance was achieved in various ways. On some occasions, young people directly  
847 contradicted stereotypes attached to their diagnosis (Honkasilta et al., 2016; Jones et al., 2015;  
848 Leavey, 2005; Mogensen and Mason, 2015).

849 *“we are not stupid... we can think for ourselves” (Mogensen and Mason, 2015, p. 261)*

850 Other participants articulated moral arguments that invalidated discrimination and the  
851 individuals who practiced it (Jones et al., 2015; Mogensen and Mason, 2015).

852 *“Who you call retard is my friend and if you call me retard I’m not going to talk to you*  
853 *because it’s obvious that you do not respect what’s inside. You respect what’s on the*

854 *outside. You judge people before you even know them and that's wrong* (Jones et al.,  
855 2015, p. 1498)

856 Other young people resisted stigma by normalising their diagnosis (Daley and Weisner, 2003;  
857 Elkington et al., 2012; Honkasilta et al., 2016; Kendall et al., 2003). They trivialised the  
858 symptoms themselves (e.g. presenting ADHD as merely *"small problems with self-control"*  
859 (Honkasilta et al., 2016, p. 253)) or their effect on their life (Daley and Weisner, 2003; Lingam  
860 et al., 2014; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2009).

861 *"It just means I have to do things a little differently, but I can still do them. I can still*  
862 *have a normal life"* (Daley and Weisner, 2003, pp. 37–38)

863 For those who minimised the severity of their difficulties, their diagnosis was simply one *"part*  
864 *of who they were"* (Kendall et al., 2003, p. 123) rather than the defining event of their life.  
865 Several studies noted a tendency for young people to describe their difficulties in purely  
866 behavioural terms, rather than medicalised terminology of symptoms and disorders (Cooper  
867 and Shea, 1998; Moses, 2009; Pope, 2015). Young people, usually with emotional disorders,  
868 also normalised their difficulties by emphasising the common nature of mental health problems  
869 (Elkington et al., 2012; Floersch et al., 2009; Moses, 2010; Wisdom and Green, 2004).

870 *"everybody has something wrong with them"* (Elkington et al., 2012, p. 303)

871 The final and most negative response to stigma was to internalise it. The processes of self-  
872 devaluation described above enlighten how a diagnosis' undesirable connotations could be  
873 absorbed into a person's identity. In eight articles, the stigma associated with a diagnosis  
874 fostered shame, embarrassment or humiliation (Elkington et al., 2012; Hallberg et al., 2010;  
875 Ingesson, 2007; Jones, 2012; Karterud et al., 2015; Kendall et al., 2003; Kranke et al., 2011,  
876 2010).



900 published in a diverse range of journals. One key contribution of this review is therefore to  
901 collate and synthesise this disparate literature. This paper's value lies in providing an accessible  
902 first port-of-call for researchers, practitioners and laypeople interested in understanding how  
903 diagnosis impacts pragmatically, emotionally and socially on children and adolescents.

904 The thematic synthesis identified numerous implications that diagnosis holds for young  
905 people's self-concept and social identity. A diagnosis can be experienced as a threat to a young  
906 person's established self-concept and can lower self-worth by implying inferiority and  
907 incapacity. However, a diagnosis can also be marshalled to promote a positive self-concept by  
908 facilitating greater self-understanding, legitimising and mitigating culpability for emotional  
909 and behavioural difficulties, and sensitising young people to their unique attributes and  
910 abilities. A diagnosis can negatively affect a young person's social identity by exposing them  
911 to stigma, and some young people feel their diagnosis invalidates them in others' eyes and  
912 leads to social alienation and interpersonal strife. Yet a diagnosis can also promote  
913 interpersonal tolerance and prompt the development of enriching relationships with similar  
914 others. Moreover, young people engage in creative cognitive strategies to bolster their social  
915 status, and a diagnostic label can be an important resource in facilitating self-protective social  
916 comparison processes.

917 The diversity in diagnoses' implications for self-concept and social identity is undoubtedly  
918 matched by the diversity in young people's relationships with their diagnosis. Different  
919 orientations to a diagnosis were apparent both between individuals and within individuals at  
920 different time points. The process of assimilating a diagnosis is a gradual one, and young people  
921 can fluctuate through numerous stages of acceptance, rejection and ambivalence towards their  
922 diagnosis. Given this diversity in diagnostic responses and outcomes, one important emergent  
923 question is whether any meaningful patterns underlie the variation. For instance, do responses

924 to diagnosis systematically differ according to demographic, contextual or clinical variables?

925 The literature reviewed revealed some suggestive patterns in this regard.

926 First, it must be emphasised that while speaking of ‘diagnosis’ in general terms is useful in

927 orienting attention towards a defined stage in the clinical process, the variation in the specific

928 diagnoses offered means that as a global concept, ‘diagnosis’ has limited conceptual value. The

929 various diagnoses available within psychiatric diagnostic systems capture radically different

930 symptoms that have equally disparate practical implications and socio-cultural connotations.

931 The literature reviewed suggests some trends in specific diagnoses’ differential effects on self-

932 concept and social identity. For instance, the tendency to reconstruct symptoms as positive or

933 life-enhancing, and thereby promote a positive self-concept, was more prominent in samples

934 with ASD (Daley and Weisner, 2003; Humphrey and Lewis, 2008; Huws and Jones, 2015;

935 Jones et al., 2015; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015) than affective

936 disorders. However, the greater prevalence of affective disorders and their continuity with

937 universal facets of human emotion made them easier to normalise and de-stigmatise (Elkington

938 et al., 2012; Floersch et al., 2009; Moses, 2010; Wisdom and Green, 2004). Elkington et al.

939 (2012) suggest youth with psychotic disorders experience more blatant forms of prejudice than

940 nonpsychotic diagnoses. Such findings are consistent with research demonstrating a hierarchy

941 of diagnoses in adult populations, with psychotic disorders more stigmatised than mood

942 disorders (Angermeyer and Dietrich, 2006). Yet the patterns suggested by the current literature

943 review remain inconclusive, since very few studies directly compared individuals with

944 different diagnostic classifications. Further confusions arise from the inconsistency in studies’

945 approaches to determining diagnostic status, with some using self-reports, others clinician-

946 reports, and others providing no relevant information. Moreover, the studies reviewed focused

947 on a limited set of diagnostic populations, most prominently ADHD and ASD. Young people

948 with psychotic, affective, anxiety and eating disorders are under-represented in this literature.

949 Neither is there representation of young people who may qualify for a diagnosis, but who have  
950 avoided or withdrawn from the mental health system. This is understandable given most  
951 recruitment methods' reliance on purposive sampling through clinics or services. Nonetheless,  
952 tapping into populations who have rejected any diagnostic classification is necessary to develop  
953 a comprehensive understanding of diagnosis' effects. One limitation of the review is the  
954 difficulty disentangling the degree the processes identified followed from the diagnostic label  
955 itself, versus the symptoms that presumably preceded it. To fully isolate the effects of a  
956 diagnostic label, research would need to compare groups of children who hold a diagnosis but  
957 no debilitating symptoms, and who hold symptoms but no diagnosis. This scientifically ideal  
958 scenario may be challenging to achieve, given the former group are likely rare (and difficult to  
959 define, given the subjective nature of symptom severity), and the latter very challenging to  
960 sample. Nevertheless, some effort to track the longitudinal outcomes of young people who  
961 display equivalent symptoms but never receive a diagnosis would be very helpful in  
962 understanding the unique effects of diagnostic labels.

963 Another variable that might differentiate outcomes is the age the diagnosis is received. Young  
964 people who received a delayed diagnosis generally believed an earlier diagnosis would have  
965 improved their life (Cheung et al., 2015; Huws and Jones, 2008; Mogensen and Mason, 2015).  
966 Again, the literature reviewed does not facilitate any definitive conclusions regarding the  
967 optimal age to receive a psychiatric diagnosis. Most research has been conducted with older  
968 adolescents: only five studies included children younger than 10 years (Brady, 2014; Kendall  
969 et al., 2003; Singh et al., 2010; Singh, 2011; Skovlund, 2014). Understanding how young  
970 children respond to diagnostic classifications should be a priority for future research.

971 Further demographic imbalances in the literature relate to gender. Males were more represented  
972 in these studies than females: a rough estimate, based only on studies that specified the  
973 sample's gender breakdown, is that 340 females and 456 males participated in the research

974 reviewed. This may reflect studies' focus on ASD and ADHD, which have higher prevalence  
975 among males. No studies sought to directly investigate potential gender differences in  
976 responses to diagnosis. Issues specific to LBGQTQI populations were similarly neglected.  
977 Furthermore, few studies specifically explored cultural or ethnic factors (Chavez et al., 2012;  
978 Cheung et al., 2015; Elkington et al., 2013, 2012). This is a highly significant gap, given  
979 extensive evidence of cultural and ethnic differences in experience of and attitudes towards  
980 mental illness (U.S. Department of Health and Human Services, 2001). The studies reviewed  
981 were predominantly conducted in North American and European countries. This may partly be  
982 an artefact of the review's inclusion criteria, which restricted the review to English-language  
983 publications. However, it should be noted that numerous included studies were conducted with  
984 non-English speaking populations, with data translated for publication (Avisar and Lavie-  
985 Ajayi, 2014; Chavez et al., 2012; Cheung et al., 2015; Hallberg et al., 2010; Honkasilta et al.,  
986 2016; Ingesson, 2007; Karterud et al., 2015; Skovlund, 2014; Tidefors and Strand, 2012).

987 The difficulty reliably segmenting findings across demographic or clinical variables partly  
988 follows from the review's exclusive focus on qualitative research. This has formed the  
989 dominant methodological approach for research on this topic thus far, for the reasons outlined  
990 in the Introduction. The value of qualitative research lies in affording a rich, nuanced insight  
991 into the range of perspectives and experiences that exist in a given social context. Qualitative  
992 research is not generally concerned with performing direct comparisons between predefined  
993 groups of participants: this is a task more suited to quantitative designs. Future quantitative  
994 research should seek to clarify the clinical and demographic variables that correlate with the  
995 varied responses to diagnosis revealed by the qualitative literature. Quantitative research may  
996 be particularly helpful in identifying 'clusters' of variables relating to the child (e.g. gender,  
997 age, IQ), their social context (e.g. familial and cultural variables) and the diagnosis in question,  
998 which reliably predict adaptive and detrimental outcomes. This would help clinicians, families

999 and young people themselves anticipate the likely outcomes in a particular case, and adapt their  
1000 diagnostic decisions accordingly.

1001 This said, one lesson of the qualitative literature reviewed is the sheer complexity of  
1002 individuals' psychological and social responses to diagnosis. It may not be possible to predict  
1003 cases where receiving a diagnosis leads to unambiguously positive or negative outcomes, since  
1004 divergent responses exist within as well as between individuals. A diagnosis may prompt  
1005 negative self-evaluations that would not otherwise have arisen, yet may simultaneously afford  
1006 a valuable sense of self-understanding and means of repairing damage to the self-concept.  
1007 Similarly, a diagnosis may expose a young person to stigma they would not otherwise  
1008 experience, yet may also be a gateway to new social identities and rewarding relationships.  
1009 These multifaceted implications for self-concept and social identity function alongside  
1010 diagnosis' equally complex implications on other emotional, practical, social and clinical levels  
1011 (Callard et al., 2013; Jutel, 2009; Perkins et al., 2018). Deciding whether to give, seek or accept  
1012 a diagnosis requires complex calculations that weigh up the costs and benefits it is likely to  
1013 afford for a certain individual in a certain context. It is particularly important to raise awareness  
1014 of this complexity among clinicians: while clinical rationale may remain paramount in  
1015 diagnostic decisions, clinical outcomes will undoubtedly be compromised if a diagnosis  
1016 impairs a young person's self-worth or social relationships. Clinical benefits must therefore be  
1017 balanced against psychological and social risks. If these risks are high, clinicians and service-  
1018 users may opt to decline or defer a diagnosis, or to implement strategies for communicating  
1019 and conceptualising diagnoses that offset risks and encourage the positive social and self-  
1020 processes revealed by this review.

1021 Greater attention to theoretical development is critical for developing such targeted strategies  
1022 to mitigate the negative repercussions diagnoses can have. Many of the studies included in this  
1023 review were atheoretical, and studies that did specify a theoretical framework drew on very

1024 disparate conceptual perspectives. This may reflect the relative youth of the field: only one  
1025 study was identified pre-2000 (Cooper and Shea, 1998) and 63% ( $n=24$ ) were published since  
1026 2010. To capitalise on empirical insights and streamline the complexity of factors involved,  
1027 theoretical development should be prioritised. This may involve both generating new theories  
1028 and borrowing from established theoretical frameworks. For instance, understanding how  
1029 cultural representations of mental illness interact with individual self-concept would benefit  
1030 from incorporating insights from social psychological theories of social categorisation, social  
1031 identity, social representations, stigma, prejudice and intergroup relations. Research and  
1032 clinical practice would be particularly served by theoretical frameworks that incorporate the  
1033 multiplicity of responses to diagnoses, and attempt to disentangle and predict the  
1034 simultaneously positive and negative implications diagnosis may have.

1035 The surge in publications post-2010 may reflect the relatively recent attention to child-centred  
1036 research and policy (LeFrancois, 2007; Sinclair, 2004; Singh, 2007). The literature reviewed  
1037 clearly demonstrates the value of research on the first-person lived experience of young people  
1038 with psychiatric diagnoses. The research uncovered novel experiences that have been largely  
1039 neglected in debates about youth psychiatric diagnosis; for instance, young people's strong  
1040 dislike of preferential treatment, and the creativity with which young people marshal and  
1041 interpret diagnostic classifications to serve their self-concept and social identity needs.  
1042 Acknowledging the active, pragmatic ways children negotiate diagnoses and therapies is  
1043 critical to ensure debates about youth psychiatric diagnosis avoid perpetuating paternalistic  
1044 views of children (Singh, 2011). It is also important to recognise common themes in debates  
1045 about diagnosis that did not emerge in this empirical literature: for instance, few young people  
1046 mentioned the media as a source of stigma or the proposed 'self-fulfilling prophecy' effects of  
1047 diagnosis. This is not evidence that such concerns are invalid or insignificant, but it is notable  
1048 they do not feature strongly in young people's first-person experience.

1049 The review has several methodological limitations which should be acknowledged when  
1050 considering its results. First, due to resource restrictions, the search did not include grey  
1051 literature or material published in books. Since much qualitative research is published outside  
1052 peer-reviewed journals (Grant, 2004), this may have excluded some relevant studies. The  
1053 review was also restricted to studies published in English, and the lack of standardised terms  
1054 for indexing qualitative research in electronic databases meant the search relied on a  
1055 purposively-selected set of keywords. Second, a systematic review protocol was not registered  
1056 in advance of completing the review. Third, an analytical priority on capturing common themes  
1057 across the literature, as well as the diversity of studies' methodological approaches, meant that  
1058 it was not possible to conduct detailed subgroup analyses. The precise ways results diverge  
1059 across age, gender, culture and diagnostic category therefore remain unclear.

1060 These limitations notwithstanding, this review is the first to systematically collate, evaluate  
1061 and synthesise studies of this important topic. The review contributes to the heated debate  
1062 currently underway regarding whether dominant systems of psychiatric diagnosis are fit-for-  
1063 purpose, particularly in youth contexts (Callard et al., 2013; Hyman, 2010; Insel et al., 2010;  
1064 Rutter, 2011; Timimi, 2014). While most prior debate has focused on reliability and validity  
1065 issues, the current review draws attention to the social and psychological outcomes that ensue  
1066 from the meanings people derive of their diagnosis. Diagnoses are not purely clinical  
1067 judgements that occur in a vacuum: they have pragmatic repercussions, which are central to  
1068 real-world diagnostic decisions. In deciding whether to pursue or accept a diagnosis, clinicians,  
1069 parents and young people themselves must trade off its potential risks and benefits, which are  
1070 specific to the child's individual characteristics, familial circumstances, cultural environment,  
1071 and institutional structures where access to educational and/or health resources may be  
1072 contingent on diagnostic status. The current review aims to inform these decisions by collating  
1073 the positive and negative implications a diagnosis can have for a young person's self-concept

1074 and social identity. Further research is needed to clarify which self and identity outcomes can  
1075 be expected in a given set of circumstances, and to establish how self and identity effects  
1076 interact with diagnoses' other clinical, practical, social and emotional ramifications.

1077

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## Tables

1416 *Table 1: Inclusion & exclusion criteria*

<b>Inclusion Criteria</b>
a. Primary, original research
b. Published in peer-reviewed journal
c. Study sample primarily children or adolescents (i.e. majority of participants must be <18 years; if sample includes any additional older participants, they must be <25 years)
d. Sample purposively selected for having a recognised, DSM-listed psychiatric diagnosis
e. Results illuminate how diagnosis affects self and/or identity
f. Presents original qualitative data and analysis (including qualitative elements of mixed-methods studies)
<b>Exclusion criteria</b>
a. Study not published in English
b. Review, commentary, theoretical or case-study ( $N < 3$ ) papers
c. Studies exploring adults' perspective on children's diagnosis
d. Studies exploring how children react to other people's diagnosis (e.g. peers, parents)
e. Studies exploring non-psychiatric medical diagnoses
f. Studies exploring aspects of mental health beyond diagnosis (e.g. treatment)
g. Studies whose results do not address self and/or identity

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1419 *Table 2: Articles included in review*

ID	Article	Region	Diagnosis	Sample size	Sample gender	Sample age
1	Avisar and Lavie-Ajayi (2014)	Israel	ADHD	N=14	6F, 8M	Range = 12.5-16.5
2	Boughtwood and Halse (2010)	Australia	Anorexia nervosa	N=25	All F	Mean = 14.8
3	Brady (2014)	UK	ADHD	N=7	1F, 6M	Range = 6-15
4	Chavez, Mir and Canino (2012)	Puerto Rico	Range of diagnoses*	N=60*	21F, 39M	Range = 12-18
5	Cheung, Wong, Ip, Chan, Lin, Wong, and Chan (2015)	Hong Kong	ADHD	N=40	13F, 27M	Range = 16-23; mean = 18
6	Cooper and Shea (1998)	UK	ADHD	N=16	6F, 10M	Range = 11-16
7	Daley and Weisner (2003)	USA	Developmental delay	N=23	10F, 13M	Range = 17-19; mean = 18.2
8	Elkington, Hackler, McKinnon, Borges, Wright, and Wainberg (2012)	USA	Range of diagnoses*	N=24	10F, 14M	Range = 13-24; mean = 18.1
9	Elkington, Hackler, Walsh, Latack, McKinnon, Borges, Wright, and Wainberg (2013)	USA	Range of diagnoses*	N=20	9F, 11M	Range = 16-24
10	Floersch, Townsend, Longhofer, Munson, Winbush, Kranke, Faber, Thomas, Jenkins, and Findling (2009)	USA	Range of diagnoses*	N=20	11F, 9M	Range = 12-17; mean = 14.75
11	Hallberg, Klingber, Setsaa, and Moller (2010)	Sweden	ADHD	N=10	5F, 5M	Range = 13-18
12	Honkasilta, Vehmas, and Vehkakoski (2016)	Finland	ADHD	N=13	2F, 11M	Range = 11-16; mean = 13.7
13	Humphrey and Lewis (2008)	UK	Asperger's syndrome	N=20	Unspecified	Range = 11-17
14	Huws and Jones (2008)	UK	Autism	N=9	3F, 6M	Range = 16-21
15	Huws and Jones (2015)	UK	Autism	N=9	3F, 6M	Range = 16-21
16	Ingesson (2007)	Sweden	Dyslexia	N=75	27F, 48M	Mean = 19
17	Jones (2012)	USA	Intellectual and developmental disabilities	N=51	13F, 38M	Range = 11-20; mean = 15.97
18	Jones, Gallus, Viering, and Oseland (2015)	USA	ASD	N=10	2F, 8M	Range = 13-20; mean = 16.24
19	Karterud, Risør, and Haavet (2015)	Norway	Non-epileptic (psychogenic) seizures	N=11	All F	Range = 14-24
20	Kendall, Hatton, Beckett, and Leo (2003)	USA	ADHD	N=39	13F, 26M	Range = 6-17; mean = 11.2
21	Kranke, Floersch, Kranke, and Munson (2011)	USA	Range of diagnoses*	N=27	18F, 9M	Range = 12-17; mean = 14.4

22	Kranke, Floersch, Townsend, and Munson (2010)	USA	Range of diagnoses*	N=40	24F, 16M	Range = 12-17; mean = 14.2
23	Krueger and Kendall (2001)	USA	ADHD	N=11	3F, 8M	Range = 13-19
24	Leavey (2005)	Canada	Range of diagnoses*	N=13	6F, 7M	Range = 17-23
25	Lingam, Novak, Emond, and Coad (2013)	UK	Developmental Coordination Disorder	N=11	4F, 7M	Range = 11-16
26	McCann, Lubman, and Clark (2012)	Australia	Depression	N=26	16F, 10M	Range = 16-25; mean = 18
27	McLaughlin and Rafferty (2014)	UK	Asperger's syndrome	N=6	1F, 5M	Range = approx. 14-18
28	Mogensen and Mason (2015)	Australia	Autism	N=5	2F, 3M	Range = 13-19
29	Moses (2009)	USA	Range of diagnoses*	N=54	20F, 34M	Range = 12-18; mean = 14.9
30	Moses (2010)	USA	Range of diagnoses*	N=56	21F, 35M	Range = 12-18; mean = 14.9
31	Pope (2015)	USA	Range of diagnoses*	N=100*	All F	Range = 11-20; mean = 15.8
32	Singh (2011)	UK	ADHD	N=150*	Unspecified	Range = 9-14
33	Singh, Kendall, Taylor, Mears, Hollis, Batty, and Keenan (2010)	UK	ADHD	N=16	2F, 14M	Range = 9-14
34	Skovlund (2014)	Denmark	Range of diagnoses*	N=8	Unspecified	Range = 7-11
35	Tidefors and Strand (2012)	Sweden	ADHD	N=11	All M	Range = 14-19; mean = 16.2
36	Travell and Visser (2006)	UK	ADHD	N=17	Unspecified	Range = 11-16
37	Wisdom and Green (2004)	USA	Depression	N=22*	13F, 9M	Range = 14-19; mean = 16.3
38	Woodgate (2006)	Canada	Depression	N=14;	11F, 3M	Range = 13.5-18; mean = 14

1420 \*See further details in Appendix A