Lived experiences of diagnostic shifts in child and adolescent mental health contexts: A qualitative interview study with young people and parents

Cliodhna O'Connor, PhD[1,2] & Fiona McNicholas, MD FRCPsych[2,3,4]

[1]*School of Psychology, University College Dublin, Dublin, Ireland*

[2]*School of Medicine, University College Dublin, Dublin, Ireland*

[3]*Our Lady's Children's Hospital Crumlin, Dublin, Ireland*

[4]*Lucena Clinic, Dublin, Ireland*

Author contact details:

Dr Cliodhna O'Connor
Email: Cliodhna.OConnor1@ucd.ie
Phone: +353 (0)1 716 8612
ORCID: 0000-0001-8134-075X

Prof Fiona McNicholas
Email: Fiona.Mcnicholas@ucd.ie
Phone: +353 (0)1 716 6603
ORCID: 0000-0001-9428-6908

Author contributions: CO'C contributed to study design, data collection, data analysis, data interpretation and writing the manuscript. FM contributed to study design, data analysis, data interpretation and editing the manuscript.

Conflict of interest: The authors declare that they have no conflicts of interest to report.

Funding: The research was funded by the European Union's Horizon 2020 research and innovation programme under grant agreement 702970.

Acknowledgements: Research assistance was provided by Ellen Dempsey, Aisling Douris and Claire Mac Bride. The authors would like to thank all who helped publicise the participant recruitment adverts and the families who volunteered their time to participate in the study.

Ethics: The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects were approved by University College Dublin's Human Research Ethics Committee, ref LS-17-105-OConnor-McNicholas.

Lived experiences of diagnostic shifts in child and adolescent mental health contexts: A qualitative interview study with young people and parents

Psychiatric diagnoses are important resources in helping young people and families make sense of emotional or behavioural difficulties. However, the poor reliability of diagnoses in childhood means many young service-users experience their diagnosis being removed, revised or supplemented over time. No previous research has investigated how young service-users experience, understand or respond to alteration of their original diagnosis. The current study adopted a qualitative approach to explore the lived experience of diagnostic shifts in child and adolescent mental health contexts. Narrative interviews were conducted with families living in Ireland, who had direct experience of diagnostic shifts. Participants included 21 parents (19 female) and 14 young people (8 female, mean age=14). Thematic analysis explored the range of interpretations and implications of diagnostic shifts in families' lives, identifying three themes that underpinned participants' narratives. *Diverse Trajectories & Experiences* outlined the variety of contexts for diagnostic shifts, ways they were communicated to parents and young people, and their clinical consequences. *A Process of Readjustment* captured processes of emotional and conceptual adaptation in the aftermath of a diagnostic shift. Finally, *Social Repositioning* explored how diagnostic shifts could prompt changes to interpersonal relations, social identity and stigma experiences. The study shows that diagnostic shifts carry significant emotional, social and practical repercussions. While diagnostic shifts may threaten the therapeutic relationship and service-user understanding, they also offer opportunities to enhance young people's self-concept, social relationships and therapeutic engagement. Clinician awareness of the socio-emotional implications of diagnostic shifts is vital to inform sensitive communication and support strategies.

Keywords: diagnosis; child and adolescent mental health; parents; qualitative

Psychiatric diagnosis is currently a controversial topic (Bhugra et al., 2017; Boyle & Johnstone, 2014; Stephan et al., 2016). One focus for criticism of prevailing systems of psychiatric diagnosis is diagnostic categories' poor temporal and inter-rater reliability (Freedman et al., 2013). Epidemiological and clinical studies show this problem is particularly acute in childhood diagnoses (Blázquez et al., 2019; Copeland et al., 2013; Costello et al., 2003; Ford et al., 2017; O'Connor, Downs, et al., 2019; Pettit et al., 2005). The low reliability of many childhood diagnoses means that during engagement with child and adolescent mental health services, a diagnosis once received can be lost, replaced or supplemented by a different diagnostic classification (O'Connor, Downs, et al., 2019). Such 'diagnostic shifts' may have profound implications for young people and their families, given diagnoses' significance in making sense of emotional and behavioural difficulties (O'Connor et al., 2018; Perkins et al., 2018). Drawing on qualitative interviews with young people and parents, the current paper reports the first study of how diagnostic shifts can affect the lives of young service-users.

Epidemiological studies that longitudinally track children's psychopathological trajectories show that transitions between different diagnostic categories occur frequently and at above-chance levels (Copeland et al., 2013; Costello et al., 2003). Most diagnostic categories seem liable to longitudinal transition (Copeland et al., 2013), with particularly high temporal cross-over between mood and anxiety disorders (Burke et al., 2005; Copeland et al., 2013; Costello et al., 2003; Kim-Cohen et al., 2003), Attention Deficit Hyperactivity Disorder (ADHD) and oppositional defiant/conduct disorders (Costello et al., 2003; Lahey et al., 2002), and conduct and mood/anxiety disorders (Burke et al., 2005; Kim-Cohen et al., 2003; Lahey et al., 2002). This evidence from community samples implies that numerous children attending mental health services experience a diagnostic shift during their service engagement. This is confirmed by a study of the clinical records of 12,543 youths attending British mental health services, which found approximately one in five had their original psychiatric diagnosis later revised or

supplemented (O'Connor, Downs, et al., 2019). Diagnostic adjustments can occur for many reasons, including the onset of new symptoms, divergence of clinical opinion, and revision of diagnostic criteria.

Diagnosis is a key inflection point in most mental health trajectories, orienting clinical attention and therapeutic strategies (Cooper & Sartorius, 2013; Craddock & Mynors-Wallis, 2014). Clinicians may welcome diagnoses' role in aetiological and prognostic inference. Additionally, in many healthcare settings diagnoses have important administrative functions, for example determining access to specialist services (Halpin, 2016; Rost et al., 1994; Skellern et al., 2005; Whooley, 2010). Institutions such as education and social welfare systems may also rely on diagnostic information to allocate resources. Thus, revision of diagnosis could affect the supports available to a young person inside and outside the clinic.

The potential repercussions of diagnostic shifts extend beyond service provision because diagnosis is not purely a clinical act, but an important socio-emotional signifier. A diagnosis is often perceived to explain puzzling or distressing behaviours, affording a sense of understanding that can be deeply valued by both young people (Huws & Jones, 2008; Kranke et al., 2011; Mogensen & Mason, 2015) and their parents (Ahern, 2000; Russell & Norwich, 2012; Singh, 2004). Some families experience the diagnosis as a relief, confirming that parents or children were not to blame for the difficulties experienced (Leavey, 2005; Mogensen & Mason, 2015; Singh, 2004, 2011). However, diagnosis can also provoke grief or despair at being marked 'different' or 'disordered' (Elkington et al., 2012; Jones et al., 2015; Kranke et al., 2010; Leavey, 2005; Mogensen & Mason, 2015). A recent systematic review confirms the range of complex and sometimes contradictory effects psychiatric diagnosis may have on young people's self-concept and social relations (O'Connor et al., 2018). While a diagnosis can lead to social alienation, invalidation and stigmatisation, some find diagnoses helpful in achieving a sense of social identification and acceptance. Similarly, although diagnosis can

sometimes devalue and threaten the developing self-concept, it can also facilitate self-understanding, self-legitimation and self-enhancement (O'Connor et al., 2018). Different psychiatric diagnoses may elicit divergent responses due to the highly variable cultural, emotional and pragmatic associations with specific diagnoses (Angermeyer & Dietrich, 2006).

Despite the frequency of diagnostic shifts and the differential significance of specific diagnostic labels, no research has investigated the impact of changing diagnoses on the young people and families affected. Understanding the first-hand experiences of service-users, including children, is critical for effective design and delivery of mental health services (Bhugra et al., 2017). Questions regarding service-user experience are particularly appropriate targets for qualitative methods (Braun & Clarke, 2019; Southam-Gerow & Dorsey, 2014). Qualitative designs apply systematic techniques to develop in-depth analyses of the subjective perspectives of a defined group of people. While qualitative research does not aim to generalise findings (Braun & Clarke, 2013; Hollway & Jefferson, 2013; Joffe & Yardley, 2003; Yardley, 2008), elucidation of the range of lived experiences of a phenomenon is especially useful when limited prior evidence precludes prespecified hypotheses or measures. The current study explores the lived experience of diagnostic shifts in youth mental health via narrative interviews with young service-users and their parents. In line with critical realist epistemology, the priority is not determining the scientific validity of clinical decisions, but rather their interpretations and implications in families' lives.

Method

Study Context

The study took place in the Republic of Ireland in 2018-19. In Ireland, most specialist mental healthcare for minors is delivered by state-funded Child and Adolescent Mental Health Services (CAMHS), which comprise multidisciplinary outpatient and inpatient services

dispersed across the country (Kerin, 2014). CAMHS are accessed free of charge through referral from a general practitioner (family doctor). However, long waitlists (several months at time of this study) prompt some families to pay private mental health professionals for diagnostic and/or therapeutic services. Relevant to the current study, CAMHS do not consider Autism Spectrum Disorder (ASD) a mental health disorder and so do not offer specialist ASD supports, which are primarily delivered by educational and disability services.

Participants

Families with direct experience of diagnostic shifts in child and adolescent psychiatry were recruited through adverts in mental health clinics and communication-channels of voluntary organisations. Adverts sought families with a young person (YP) aged under 18, who had experienced their original psychiatric diagnosis being later removed/revised/supplemented. As a key sampling aim of exploratory qualitative research is to maximise the diversity of perspectives and experiences (Bauer & Aarts, 2000), no further inclusion criteria were imposed. Interested parents contacted the researcher to arrange participation.

Twenty-one parents (19 female) and 14 (8 female) of their children agreed to participate. This represents a typical sample size for qualitative research (Vasileiou et al., 2018). Six parents were aged between 30-39, eight 40-49 and seven 50-54. Thirteen were married/cohabiting, with the remainder single/separated. Participants lived in a range of rural and urban locations; all were of Irish origin except three white Britons. Eleven had undergraduate-level education and thirteen worked outside the home. Table 1 displays YPs' characteristics as reported by parents. In line with the critical realist aim of reflecting participants' perspectives, Table 1 displays the diagnostic classifications reported by parents, which did not always align with standard diagnostic manuals (e.g. 'pathological demand avoidance' does not feature in the DSM or ICD, but was reported by Harriet as a distinct clinical diagnosis her son had received).

Where possible, parents provided documentation (e.g. clinic letters) to substantiate reported diagnostic trajectories.

***Table 1.** Participant pseudonyms and YP characteristics*

Procedure

Ethical approval was granted by the University College Dublin Human Research Ethics Committee. Parents gave informed consent and YPs signed assent to participate. Interviews took place in family homes. While parents and YPs were usually interviewed separately, joint interviews were facilitated if preferred. The interviewer was a research psychologist and not a clinician, nor previously known to participants. Since medical sociologists root the emotional potency of diagnosis in its power to trigger narrative (Jutel, 2019), narrative interview procedure (Jovchelovitch & Bauer, 2000) was used for both parent and YP interviews. Brief 'warm-up' questions progressed into an 'uninterrupted narration' phase by asking participants to relate, in their own words, their experience of diagnostic alteration. The interviewer refrained from intervention until the participant concluded their story. Interviews then moved into a 'questioning' stage where the interviewer sought clarification of narrative gaps. Parent interviews lasted an average of 68 minutes and YP interviews 31 minutes. Interviews were audio-recorded and transcribed with identifying details removed. Parents completed questionnaires seeking demographic (e.g. gender, age) and clinical information. Parents received modest vouchers as compensation.

Analysis

Interview data were analysed via thematic analysis (Braun & Clarke, 2006; Joffe, 2012; Joffe & Yardley, 2003). Transcripts were first inspected by one author to detect salient concepts and patterns. In discussion with the research team, these observed patterns were gradually incorporated into a codebook that captured the key features of the textual material. Codes were organised into categories reflecting similarities in manifest content (e.g. the category

'*Emotional responses*' included '*Relief'*, '*Grief'*, '*Guilt', 'Anger'*). Coding was performed using NVivo.

To establish inter-coder reliability (O'Connor & Joffe, 2020), nine interviews were independently double-coded by one author and one of three coders external to the research team. Using Landis and Koch's (1977) guidelines for interpreting reliability coefficients, Cohen's κ analyses showed 72% codes had substantial (κ>.6) reliability. Definitions of the 19% codes with moderate reliability (κ=.4-.6) were tightened and the 9% codes with κ<.4 were dropped before final coding of all transcripts. Other steps to ensure analytic rigour included maintaining an audit trail, transparent reporting of analytic procedures, 'thick description' with illustrative data excerpts, and attention to deviant cases (O'Brien et al., 2014; Palinkas, 2014).

When coding was complete, a frequency table indicating the number of interviews that contained each code revealed the most salient patterns. Conceptual links between codes were identified by inspecting their corresponding quotations, while structural links were explored through NVivo's crosstab, hierarchy chart and cluster analysis functions. These networks of inter-code relationships were visually mapped to identify overarching thematic clusters (Figure 1).

Results

Thematic analysis identified three themes: *Diverse Trajectories & Experiences, A Process of Readjustment,* and *Social Repositioning.* Their content is outlined below with supporting quotations, which are identified with a pseudonym and their participant group (*P*=Parent, *YP*=Young Person).

***Figure 1.** Thematic map**

Diverse Trajectories & Experiences

Contexts of diagnostic change

Supplementary diagnoses. As evident from Table 1, supplementation of original diagnoses with additional comorbid diagnoses was more common than retraction or substitution of diagnoses. Twelve families framed diagnostic supplementations as corrections of previously "missed" diagnoses, i.e. earlier clinicians' inattention to disorders that were indeed present. Delayed diagnosis of neurodevelopmental conditions (ASD and ADHD) was particularly common and usually attributed to insufficient clinician awareness or professionalism.

> *I don't think that they were very up to date in their knowledge [P/Orla]*
>
> *I feel like they were silly. They weren't really a proper consultant anyway. [YP/Stephanie]*

Other parents ascribed "missed" diagnoses to the subtlety of symptom expression, the tendency of one diagnosis to *"overshadow" [P/Emily]* or *"mask" [P/Caroline]* another, or the effectiveness of symptom management strategies families had developed.

> *But it was based on the thing that she could hit some social cues, but my job as a mum was to teach her cues, which I have done. So it's like we were kind of, I don't know, being punished [P/Deirdre]*

Most families had initially accepted original diagnostic ascriptions and exclusions, trusting clinical expertise and *"going with the experts' opinion" [P/Terry]*. However, ten participants reported gradually concluding the original diagnosis was only *"part of the picture" [P/Alice]* with *"something more going on" [YP/Owen]*. Parents, whose familiarity with mental health concepts grew after the initial diagnosis, often developed specific suspicions that another diagnosis was pertinent.

> *we just knew it was autism […] It just became, you know, we know this is what's going on. We have to pursue this. We'd been kind of trying to deny it for three years. You know, saying no, it's just ADHD, it's just ADHD. And it was kind of the point at which we went, no it's not. No it's not. We know this is not just ADHD. [P/Belinda]*

Most supplementary diagnoses occurred due to proactive parental requests for re-assessment. Eight families were dissatisfied with CAMHS' response to these requests and attained their diagnosis from private psychiatrists. Only three families reported a supplementary diagnosis was independently initiated by clinicians, usually following a crisis episode or hospital admission. Unlike family-driven modifications, unexpected diagnostic shifts tended to elicit resistance.

> *she would've went from the bulimia to the anxiety to the borderline. When I heard that word, I was like, Jesus Christ no, she couldn't have something like that [P/Caroline]*

Withdrawn diagnoses. Eight families reported a diagnosis being withdrawn; for four this was immediately substituted by a different diagnosis. Only one parent and one YP reported being amenable to a diagnostic retraction. Most families objected to diagnostic retractions but felt disempowered to prevent them.

> *they removed the autism diagnosis by observation. They never done another ADOS. And they've basically told me that I'm not allowed, I'm not allowed get him reassessed. [P/Emily]*

Few families viewed diagnostic retraction as evidence of genuine improvement in core symptomatology. Indeed, four framed the diagnostic loss as unfair disadvantage due to their effective symptom management.

> *he is so much better, but that is down to me. I don't mean to be big-headed but that's… I do a lot of work with him. And I feel like we're being punished because I worked so well with him. [P/Harriet]*

> *you're diagnosed with it and then you work at it and then you're better at it and you're tested and you're better at it but you still have it. But they just pick up on the better thing, so they're like, oh, you don't have it after all. But you do have it. You've just worked at it throughout. [YP/Leanne]*

Beyond explicit retractions, other cases showed how prior diagnoses may remain on clinical files but gradually recede from active clinical attention. For instance, Siobhan described how her daughter's move from CAMHS to a private psychiatrist brought a shift from a mixed anxiety-depression diagnosis to ADHD and ASD; the former diagnosis was never explicitly

retracted but ceased influencing care pathways or familial understanding. Four parents reported the family ignored or dismissed diagnoses they felt had limited utility.

> *The ODD was never mentioned really by anyone again. So we ignored that. [P/Penny]*

Thus, families or clinicians could informally drop diagnoses in practice if not in principle.

Communication of diagnostic change

Communication to parents. Most parents described clinicians' delivery of a diagnostic shift as *"matter of fact" [P/Penny]* and recalled little explanation of the rationale for the change. While many had anticipated the new diagnosis, those for whom it was unexpected experienced the news as a *"shock" [P/Caroline]*. Since the following conversation could pass in *"one big blur" [P/Harriet]*, parents appreciated clinicians' availability for follow-up questions over subsequent days. Parents valued communication approaches that limited jargon and provided accessible and up-to-date information resources. While parents felt they should initially be informed of the diagnostic shift without the YP present, they appreciated clinicians' support in devising a strategy for informing the YP. Parents also desired advice on communicating the information to other family members and schools.

Communication to YPs. Most diagnostic shifts were communicated to YPs by parents rather than clinicians. Parents differed in the extent and speed of disclosure to the YP. Nine parents withheld some diagnostic information from the YP due to concerns about their comprehension or negative behavioural repercussions, sometimes alluding to a feared 'self-fulfilling prophecy' effect of diagnostic labels.

> *I think the label is the wrong thing to give her at the moment. I think she could go backwards and into herself if she kind of knew what psychosis really meant […] I think the harm would be she'd dwell on it. She'd read into it. And she would feed into it herself. [P/Karen]*

Other parents felt transparent disclosure *"would be good for her to know" [P/Deirdre]*, but found it difficult to judge appropriate style and content of information delivery. Despite this

uncertainty, parents wished to retain control over the manner of disclosure. One mother resented that clinicians had informed her son of the diagnostic shift *"against our wishes" [P/Rose]*, while another expressed anger that clinicians had framed her daughter's ASD diagnosis as *"this awful disability" [P/Deirdre]*.

YPs generally did not describe vivid memories of *"the exact moment when they said" [YP/Hugh]* their diagnosis had altered. YPs favoured transparency throughout the re-assessment process over sudden diagnostic pronouncements.

> *They think you have ADD, next thing it's, oh you've ADHD. I'd say just slowly ease them in. [..] I'd say like, we're testing you – just like, sometimes they test you for stuff and you don't even know it. But I'd say just kind of, even if they do know it, I'd say just slowly bring it in. [YP/Niall]*

Consequences of diagnostic change

Therapeutic pathways. A common corollary of changed diagnosis was changed prognosis. In most cases, the later diagnosis was more severe or pervasive than the original diagnosis. Families sometimes struggled adjusting to a new imagined future for their YP.

> *We're looking at a different pathway for [YP]. […] Everything has adjusted. […] we really felt that we were kind of really going towards mainstream life for [YP]. […] That's a major change, you know, for ourselves. [P/Karen]*

> *you realise, this is BPD, this is chronic, and this is like, this is a really, really serious mental illness. That's where the shock I think came from for me definitely. Because this is what this is, you know that you relate to these kind of symptoms – but it's this big. [YP/Cathy]*

For many, the most immediately pressing repercussion of a diagnostic shift was modified therapeutic possibilities. Depending on the diagnostic trajectory, this could involve either improvement or narrowing of therapeutic options. Diagnoses that pointed towards accessible treatment routes, such as ADHD, were welcomed, especially if the prior diagnosis had not facilitated effective intervention.

> *I suppose the big difference then is that with the ADHD diagnosis it opens up different treatment options, so we'll say in terms of the medication piece [P/Alice]*

Conversely, two families whose ADHD diagnosis was retracted reported immediate withdrawal of stimulant medications their YP had found helpful.

> *Once CAMHS wrote to the doctor and said conclusively we are lifting the diagnosis, that was it. Prescription stops. […] there was no weaning, nothing. Done. [P/Joan]*

Almost all families who received a later diagnosis of ASD were disappointed with the specialist interventions available. Indeed, addition of an ASD diagnosis commonly *reduced* supports already in place for prior mental health diagnoses. In the Irish system, CAMHS is responsible for mental healthcare while supports for ASD in absence of mental health difficulties are delivered by disability services. Seven parents reported a late ASD diagnosis resulted in their discharge from CAMHS, without replacement supports for ongoing mental health issues. Two parents suspected diagnoses had been revised strategically to remove the YP from CAMHS' remit.

> *they took the ODD [oppositional defiant disorder] away because [CAMHS clinic] deal with ODD and they don't deal with PDA [pathological demand avoidance]. And I think they took – they must have taken ADHD sooner, probably last year. And again, I think it's because [CAMHS clinic] could have discharged him quicker without these. That was my thinking. [P/Harriet]*

A small number of diagnostic shifts did not effect changes to therapeutic pathways, which generally caused confusion about the rationale for the change.

Therapeutic engagement. A diagnostic shift could sometimes threaten the therapeutic relationship. Twelve families reported diagnostic shifts arose due to change of clinician, which usually prompted comparison of the relative merits of the individual professionals. Evidence clinicians could disagree or change their mind impeded parental trust in clinical expertise and beneficence.

> *I couldn't understand – you fought with me for three years to medicate my child. And then when I do, all of a sudden my child doesn't have this condition because somebody says so. So to me, it felt like, oh well this is a crazy mother here and there's nothing wrong with these kids, and she's a single mother to two special needs kids, she's an easy*

target, we're going to bully her and we'll victimise her and… that's the way it led me to feel. [P/Emily]

Likewise, discovery diagnoses were changeable could lead YPs to doubt their legitimacy.

I thought that people were just like putting labels on me just randomly. I thought they were just, because it was changing… I thought that, I didn't kind of believe it. [YP/Isobel]

It's like, oh, a second one, really? Are you sure about that? [YP/Stephanie]

However, diagnostic shifts could sometimes improve therapeutic relationships when new, welcomed diagnoses were interpreted as evidence clinicians understood the YP. Therapeutic engagement was also enhanced if the new diagnosis had a specifically indicated treatment; this diagnosis-treatment match made the intervention seem precisely targeted.

it did make a lot of sense with the diagnosis, with the BPD [borderline personality disorder] and then getting the DBT [dialectical behaviour therapy]. Because I'd say before I got diagnosed with BPD, say if I did do DBT, I wouldn't understand why I'm being taught this. [YP/Cathy]

A Process of Readjustment

Emotional adaptation

Positive responses. The most prevalent emotional response to a supplementary diagnosis, mentioned in 14 interviews, was relief. Prospects of improved treatment were one basis for this response. Additionally, YPs sometimes felt the new diagnosis answered questions the prior diagnosis left unresolved.

I was at the same time happy that I finally knew what was going on. It was like, it was almost like if you have a problem, like a sound going off in your car and you just don't know what it is for ages and then you finally find out what's causing it. And you get that sort of a relief. [YP/Owen]

I was really happy because I actually have a reason for being everything. [YP/Stephanie]

Parents' relief sometimes related to a sense they were absolved of culpability for the YP's continued difficulties. Diagnoses such as ASD were perceived to divert blame from the home environment, where previous emotional or behavioural diagnoses had not.

> *I was really really relieved. Because I finally knew, someone was telling me what I knew but I also could see that this is why all this has been happening. […] I found it was a validation of the approach that I had been taking and the parenting, that it wasn't my bad parenting that was causing this. Because that was what I had been led to believe before. [P/Deirdre]*

Only one parent and one YP reported they were *"grand, happy" [YP/Hugh]* at loss of a diagnosis: diagnostic retractions elicited predominantly negative reactions.

Negative responses. Nine interviews showed the predominant relief reactions were sometimes mixed with *"sadness" [P/Orla]*, *"upset" [P/Fiona]* and *"alarm" [P/Quinn]*. In particular, supplementary diagnoses perceived as more serious than prior diagnoses provoked trepidation.

> *Like a weight being taken off my shoulders and then being put back on again in some way. It's hard to explain how I felt but it just felt there was some relief and then there was some tension being put back on, like back into my life. […] I've been told I've had all these different diagnoses […] But I think being diagnosed with ADHD is probably the biggest—like it was the scariest and the most relieving and it was the most emotional diagnosis of all of them. [YP/Owen]*

Only one YP related an unambiguously negative response to hearing their new diagnosis, describing himself as *"angry, annoyed" [YP/Hugh]*. Yet YPs, who often found change intrinsically difficult, could struggle with transitioning diagnostic categories.

> *She [YP] wasn't overly happy with the change because it's a change. [P/Iris]*

> *getting something taken off and then getting something equally as unique put on is kind of... You're doing this and then plopped into a different universe where you're doing something completely different. It's—I guess it can be hard for the parents and the children as well. [YP/Jane]*

For four parents, the diagnostic shift provoked guilt they had *"missed it" [P/Nora]* or failed to prevent clinical error.

> *I felt so guilty that I didn't pick up on it. Huge and profound. […] It was profound. I had to take a year off work. It absolutely nearly killed me totally. [P/Orla]*

> *I feel I'm a failure. And I feel that I shouldn't have let them remove that diagnosis. I should have fought them more and more. And I do feel that I let [YP] down [P/Emily]*

In nine families who had experienced delay obtaining the 'correct' diagnosis, diagnostic shifts induced regret of lost opportunities for understanding and intervention. This regret was sometimes mixed with resentment at clinicians.

> *Anger. Why wasn't he diagnosed with that? Why did nobody say it to me? […] I'm filled with the anger and I keep throwing it back in their face and I say it at every appointment. Like they're giving me the utmost highest priority of care supposedly. And I'm saying, but if you had have been here three years ago, I wouldn't be needing all this. My child wouldn't have been through all this. Because if you look at [YP] now to what [YP] was two years ago, it's a completely, completely different person. [P/Emily]*

Conceptual adaptation

Understanding. Almost all families suggested the new diagnosis improved the YP's self-understanding. For certain families, the prior diagnosis had offered limited explanatory power.

> *At first, because this was all we had at first, I was like, well this makes sense and this makes sense. But I tried to pretend, like there was all those other problems I was having, just wouldn't matter at all because I had this diagnosis. Which… like I couldn't relate the other problems to this diagnosis, so it was difficult in my head. It made sense but it wasn't everything. […] When you get a diagnosis that explains one thing but doesn't explain a lot of other things [YP/Cathy]*

In such cases, the new diagnosis constituted *"the missing link" [P/Caroline]* that *"all matched up" [P/Emily]*. This improved self-understanding was perceived as intrinsically valuable.

> *I think sometimes, like the child or the young person needs an answer as to why. They might feel well I'm different, but why am I different? It takes away that, 'what's wrong with me?' I think he has an answer. So I think it's a good thing. [P/Fiona]*

Parents' understanding of their child also shifted following the new diagnosis, with parents speaking of "*suddenly having to reframe our whole understanding of [YP]" [P/Belinda]*.

> *Mum seemed to, all of a sudden seemed to have some sort of huge idea of what actually I'm going through or something like that. […] she didn't really do the same things she used to do when I was younger. I was just used to her kind of not really understanding me [YP/Ben]*

Parents felt their improved understanding led to *"more compassion" [P/Caroline]* for their child. For YPs themselves, improved self-understanding also facilitated self-acceptance and

mitigated self-condemnation for undesirable traits, which were reframed as *"just another part of myself […] something I can learn to live with." [YP/Owen]*.

> *you can't really accept something if you don't know what you're accepting. Like if you don't - say if I didn't have the diagnosis, it would be hard for me especially to accept that this is who I am if I don't know why I'm like this or I don't know what this is or what it's called. [YP/Cathy]*

The self-understanding facilitated more effective symptom management. YPs described specific strategies they used to *"help control" [YP/Richard]* their named disorder, while parents felt newly empowered to implement informed behaviour management strategies.

> *when it was finally confirmed it was, right, okay, now I can start working out how to cope and how to deal with it. I just felt I was in an uphill battle in that intervening time. I'd felt I was trying to fit structures and things and it just wasn't fitting and I couldn't understand what it was that, you know, I wasn't helping him. [P/Belinda]*

Confusion. Revised diagnoses did not universally benefit YPs' self-concepts: twelve interviews suggested psychiatric diagnoses threatened YP self-image. YPs could interpret the multiplicity of diagnoses as evidence there was something irredeemably wrong with them.

> *it's kind of tough for an eight-year-old to figure out she's been diagnosed with so much. Another thing on her back [YP/Jane]*

Difficulty conceptually grasping multiple changing diagnoses was reflected in some uncertainty among YPs about their current diagnostic status.

> *I don't know which ones are gone and which ones are, like, still there. [YP/Hugh]*

Parents also expressed confusion about the rationale for supplementary diagnoses.

> *I kind of thought, God, why are you giving my child all these labels. You know, like parts of this are just part of autism anyway. And I really felt like, is this beneficial? [P/Iris]*

Nine families dealt with the conceptual complexity of multiple comorbid diagnoses by organising them into a hierarchy where one diagnosis took centrality, with others' explanatory function limited to specific contexts.

> *it's like saying BPD is like a circle and social anxiety bubbles that circle […] and the ADHD is around that. […] it's these big bubbles within each other. The main one in the*

> *middle is the one that does cause the most problems but that doesn't mean the other bubbles aren't there. [YP/Cathy]*

Two participants (Emily and Harriet) related particularly complex diagnostic trajectories involving the addition and retraction of numerous neurodevelopmental and behavioural diagnoses, reportedly without prior parental consultation. Emily and Harriet experienced this diagnostic vacillation as dispiriting indication of professionals' inability to understand their YP. Another mother had initiated legal action to have the word "*dilemma*" removed from her YP's clinical file, having interpreted the word as meaning *"that no one could help then. It meant that no one could, no one was willing to kind of try anything else. It was kind of like a wash the hands feeling. That we're dialling out. It really kind of hurt" [P/Karen].*

Social Repositioning

Interpersonal relations

Within the home. Ten interviewees suggested the diagnostic shift had affected the parent-YP relationship. A revised diagnosis often prompted parents to modify their parenting behaviours to incorporate strategies purportedly effective for the new diagnosis.

> *I have to learn how to parent him in a completely different way. I was parenting him, parenting him as a child with autism and ADHD. […] But if they're saying he doesn't have it, that he has this, I need to parent him a different way. And I'm afraid that, by me parenting him for one thing, I should actually be parenting him for another. [P/Emily]*

In general, parents reported new diagnoses improved relationships with YPs by inculcating more tolerant, less censorious attitudes to challenging behaviour. While YPs acknowledged these positive developments, abrupt changes to the home environment could be disorienting.

> *Bad because they kind of literally changed everything I was used to in life or whatever when I was younger. Not that much but, you know… like Mum kind of changed what she did and always comforts me a lot […] it's just, I don't know, time to get, it's like starting getting used to your Mum all over again. [YP/Ben]*

A small number of parents believed the confusion wrought by diagnostic instability had compromised YPs' trust in their parental competence.

> *He didn't want the medication at all. He was completely against that. And that's what broke me, to find out he didn't have ADHD. And I'm after giving him medication that he didn't want, against his will, but he doesn't have it. That killed me. And he was angry about that as well. I kind of feel like I lost a bit of his trust there. Because I've been forcing this stuff down him for a diagnosis he doesn't have. [P/Harriet]*

Beyond the home. Families differed in the degree they divulged YPs' diagnoses beyond the home. Nine interviewees described a fully transparent approach, while twelve tended to conceal or selectively disclose diagnoses. Disclosing a diagnostic *shift* to schools or extended family posed particular challenges, as parents feared this would undermine the legitimacy of their YP's difficulties.

> *So when I did get her assessed and the word came back that she did have it, they [teachers] were oh so surprised and like almost, even though they had the information in the report there in front of them, not believing it. [P/Gwen]*

Thirteen participants described invoking a diagnosis to explain the YP's atypical behaviour to others. Change of diagnosis could affect this communicative capacity because specific diagnoses held differential explanatory power in specific contexts. Several families noted ASD diagnoses helped communicate their children's needs more effectively than prior diagnoses.

> *it was hard for me not having a diagnosis on the spectrum because it would have been easier for me to explain her behaviour […] Once I got the diagnosis, particularly in her teenage years when she was so violent, I was able… I was able to say look, it's not her, it's the condition. [P/Deirdre]*

While individual YPs differed in their comfort sharing diagnoses with peers, none reported specific difficulty disclosing a changed diagnosis. While no YPs described negative peer responses to diagnostic disclosure, YPs who concealed their diagnostic status were motivated by fear certain diagnoses would "*put them in a box" [YP/Deborah].*

> *I haven't even told my friends. […] I guess I don't want to be judged differently because some people will think autism is just that one thing even though, even though autism is different for everyone. Still you don't want to be judged by having autism. [YP/Jane]*

Societal relations

Stigma. Nine parents and five YPs introduced the topic of stigma or stereotypes. Parents were aware that different diagnoses carry variable intensities of stigma.

> *there is stigma around ADHD but so much less so because it's not really, people aren't really aware of it. As opposed to when you say autism, and you know, people immediately go, ugh. And they have this picture in their head about what someone who is autistic or whatever is. [P/Siobhan]*

A move from one diagnostic category to another exposed the YP to a new set of stereotypes. This sometimes motivated rejection of the new diagnosis.

> *people speak very negatively about things like ADHD and OCD [obsessive compulsive disorder] because they don't understand. You know the way people use it, oh I have OCD, I clean my house all the time. You've OCD, don't be doing that. She's a very literal person. So if someone's joking about, saying God will you ever stop, you've OCD - she takes that as negative. So she thought, I don't have OCD. And you know, ADHD is kind of used in terms of behaviour a lot of the time. So she had a negative association with them from the get-go and she didn't want them. [P/Iris]*

> *The problem is it's not just me not being able to accept myself, it's other people, I'm just worried they won't accept me or whatever. I keep thinking about it and I can't stop thinking about it. So if that magically happens, which I know it won't because we're just human, that everyone always accepts me then but doesn't treat me like I have autism all the time. Treat me normal but maybe sometimes take it a notch down or whatever. But I know that's not possible so I might as well forget it. [YP/Ben]*

The addition of multiple comorbid diagnoses heightened concerns about "labelling".

> *I didn't really like any of the terms, the OCD or the ADHD. Because I just felt like there are just so many. I said to them, I don't like labels. [YP/Isobel]*

Social identity. Most YPs were sensitive to their 'difference' from other children. While for some, receiving a psychiatric diagnosis reinforced this difference, others experienced diagnosis as normalisation. Fourteen participants referenced the importance of engaging with others who shared their diagnosis, whether family-members, peers or hypothetical others. A new diagnosis could open up novel social identities and sources of community.

> *to know that there's other people who would like accept me because they know what it's like, that's kind of reassuring. [YP/Deborah]*

Conversely, diagnostic retraction risked loss of diagnostically-linked social identities. For instance, Laura described how her two children with ADHD diagnoses developed a ritual chant of "*ADHD Unite!*"; loss of her daughter's ADHD diagnosis threatened this sibling solidarity.

Embrace of diagnostic identities was not universal. Two YPs rejected opportunities to associate with others who shared a late-received diagnosis, concluding that "*those guys are different" [P/Terry]*.

> *I'd met some people who had autism as well but they're nothing like me or whatever. I had autism but I also was… a bit half normal I suppose [YP/Ben]*

Unease at the prospect of being grouped with certain others lay behind some resistance among YPs to new diagnoses. Familial experience also meant specific diagnoses could hold personal 'baggage' that YPs did not wish to share.

> *I have anxiety. I don't know if he sees that as a negative. There are some things I'd struggle with. So I don't know, maybe seeing me struggle, he didn't want to be the same. […] that affected him loads. Having it, them giving it to him and then taking it away as well. [P/Harriet]*

> *And then it came out about the diagnosis. And [YP] – 'I don't want that diagnosis. I don't have autism. I'm not like him [YP's brother], I'm not crazy like him'. Because [YP's brother] would be kind of on the other end of the spectrum and he has pathological demand avoidance and he has a lot of others going for him. So [YP] hated being – he hates the word autism. [P/Emily]*

Thus, subjective experiences of diagnostic shift hinged on the specific meanings particular diagnoses held in YPs' familial, peer and cultural environments.

Discussion

Many previous studies have highlighted the complex social, emotional and practical ramifications of receiving a psychiatric diagnosis, particularly in early life (O'Connor et al., 2018; Perkins et al., 2018). The current study represents the first analysis of how YPs and families react when that diagnosis *changes*. It suggests that subsidiary diagnoses, which modify pre-existing diagnostic status, prompt socio-emotional processes more complex than observed

with initial diagnoses. These findings have important implications for clinical practice and ongoing debates about diagnostic classification.

In this sample, the most common form of diagnostic shift involved the addition of supplementary comorbid diagnoses, which families framed as "missed" during initial assessments. Most supplementary diagnoses were proactively sought by families, with fewer cases of clinicians initiating revision of original diagnosis. Formal retractions of diagnoses were also relatively infrequent. This coheres with a study of 3,000 diagnostic statements in electronic health records of a British CAMHS, which identified few instances of diagnostic retraction (O'Connor et al., 2020). Given documented high rates of cross-diagnosis transition in longitudinal community studies (Copeland et al., 2013; Costello et al., 2003; Ford et al., 2017), it is possible clinicians are reluctant to explicitly revise outdated diagnoses. Such reluctance may be warranted: the current study showed diagnostic retractions usually elicited negative familial responses, while contradiction of other clinicians' judgments undermined confidence in individual clinicians or the profession generally. Instead, clinicians might opt to simply ignore prior diagnoses without explicitly retracting them: the analysis suggested that with addition of a new focal diagnosis, or transfer to a different clinician, older diagnoses can recede from active clinical attention. While this may avoid the practical challenges of retrospective re-evaluation and the aforementioned threats to clinician-family or inter-clinician relations, it means YPs can carry an unnecessarily large number of diagnostic classifications. This study suggests a multiplicity of diagnoses risks confusion and self-stigmatisation. In communicating a diagnostic shift, explicitly addressing how a new diagnosis relates to prior diagnoses may be necessary to avert confusion or misinterpretation.

Clinicians implementing a diagnostic shift should be aware that emotional responses may be intense and complex. While most families experienced the new diagnosis as a relief, this was sometimes mixed with grief, anxiety, regret and self-blame. The relieving function of

diagnostic shifts was usually related to perceptions the new diagnosis better explained the YP's current difficulties. Diagnoses are important meaning-making tools for YPs conscious of the atypicality of their behaviour or emotions (O'Connor et al., 2018). Change in clinical categorisation forces reformulation of aspects of YP self-concept that hinged on prior diagnoses. While parents typically observed improvements in YPs' self-image, some YPs deplored the multiple "labels" they had been assigned. Diagnostic shifts can also re-classify YPs into different social groups, which may either provide valued new identities, or undermine bonds premised on previously shared diagnoses. These emotional and social outcomes are necessarily case-specific, dependent on the new and former diagnoses involved, and the unique meanings they hold in that YP's personal and social contexts. It is important to acknowledge that even if a diagnostic shift benefits the YP's self-understanding and therapeutic pathways, they may still require support in acclimatising to being, in the words of one young participant, "*plopped into a different universe*".

Further factors influencing the experience of diagnostic shifts are the societal preconceptions attached to specific diagnostic labels. Participants' diagnostic trajectories broadly aligned with previous findings of high heterotypic continuity between ASD, ADHD, conduct and anxiety disorders (Burke et al., 2005; Copeland et al., 2013; Costello et al., 2003; Kim-Cohen et al., 2003; Lahey et al., 2002; O'Connor, Downs, et al., 2019). Research shows such diagnoses differ in both the quantity and quality of stigma they attract (Angermeyer & Dietrich, 2006). Change of diagnosis therefore means exposing YPs to a new set of stereotypes. YPs' awareness of such stereotypes could prompt resistance to new diagnoses. However, certain directions of diagnostic shifts may reduce stigma exposure. In particular, parents whose YP moved from a behavioural to ASD diagnosis perceived better interpersonal responses to diagnostic disclosure, which they attributed to greater public awareness of ASD. This aligns with previous findings that while disclosing certain diagnoses (e.g. schizophrenia, ADHD) exacerbates stigma

(Batzle et al., 2010; Ohan et al., 2013), ASD diagnosis can ameliorate stigma (O'Connor, Burke, et al., 2019; Sasson & Morrison, 2019). As stigma processes are culturally variable (Angermeyer & Dietrich, 2006), fostering preparedness for social repercussions of diagnostic shifts requires cultural sensitivity in clinicians.

Later diagnoses of ASD also illustrated how diagnostic shifts can affect service entitlements when access is diagnostically-linked. The finding that subsidiary ASD diagnoses led to loss of prior mental health supports may be specific to the Irish context, at a time when under-resourcing of both CAMHS and disability services encourages tight enforcement of eligibility criteria. Yet internationally, many jurisdictions use diagnostic information to allocate users into services or treatment-tracks, or to distribute educational, social welfare or insurance resources (for example, contracts between US behavioral healthcare providers and state Medicaid programs may explicitly exclude behavioural issues related to a primary diagnosis of autism (Ruble et al., 2005)). While the current study did not illuminate clinicians' rationale for implementing or abstaining from diagnostic shifts, previous studies show diagnostic decision-making is highly pragmatic, with consequent service entitlement a frequent consideration (Halpin, 2016; O'Connor et al., 2020; Skellern et al., 2005; Whooley, 2010). In highlighting the service disruption caused by diagnostic shifts, the current study contributes to debates about the wisdom of premising service access on diagnosis (Allsopp & Kinderman, 2019). It also resonates with growing concerns about the pragmatic utility of categorical systems of diagnosis, relative to transdiagnostic alternatives such as dimensional (Kotov et al., 2018) or clinical staging (McGorry & Nelson, 2016) approaches.

The study provides the first data on service-users' preferences in relation to communicating diagnostic shifts to families. Parents valued follow-up opportunities, provision of independent information resources, and transparency about the clinical rationale for and pragmatic consequences of the shift. Universally, parents wished to retain control over delivery of the

news to the YP, but appreciated professionals' assistance in devising an appropriate communication strategy. Information about the common occurrence of diagnostic shifts and typical patterns of heterotypic continuity (O'Connor, Downs, et al., 2019) may help normalise the experience. YPs, who often struggled with change generally, requested that the possibility of a diagnostic shift be gradually introduced rather than abruptly announced. Given the finding that clinician-initiated diagnostic shifts elicited more negative familial responses than parentally-sought diagnoses, some 'phasing in' of diagnostic possibilities may be helpful for unsuspecting parents as well as YPs. YPs also preferred consequent modification of services or home environment to be phased in progressively to allow acclimatisation. Previous research suggests that younger age at first diagnosis increases the probability of later diagnostic shifts (O'Connor, Downs, et al., 2019); several YPs in this study, who underwent a diagnostic shift in early life (<10 years), struggled to recall or explain this experience. Communication of diagnostic shifts and their rationale should therefore be appropriately tailored to YPs' age and developmental stage. Based on this research, the project team have developed open-access resources (leaflets and animated videos for health professionals, parents and YPs of different ages) to aid clinical communication of diagnostic shifts.[1]

The qualitative analysis facilitated a rich, detailed account of first-hand experiences of diagnostic shifts. While qualitative research does not aim to produce generalisable findings, it is important to note the study reflects just one country: further international research is necessary to appraise the contextual specificity of these results. Additionally, while the sample size was typical for qualitative studies (Vasileiou et al., 2018), it was imbalanced by gender and ethnicity. Previous research suggests fathers may have different responses to their child's diagnosis than mothers (Singh, 2003), and that ethnic minority children are less likely to have their diagnosis changed (O'Connor, Downs, et al., 2019): these groups' unique experiences

[1] These can be accessed by emailing the authors or at the website https://paedsdiagnosis.ucd.ie/resources/.

should be targets of future research. The sample included families who both welcomed and regretted their diagnostic shift, which helps allay concerns the open recruitment strategy preferentially attracted dissatisfied service-users. The parent-centred recruitment process, while mandated by ethics procedures, constrained YPs' ability to opt in themselves: expansion of their perspective should be prioritised in future research. Further research should also explore clinicians' viewpoint on diagnostic shifts. The study's reliance on familial report, albeit with documentary support where available, means results are vulnerable to distortions of memory, knowledge or social desirability. This is less problematic for critical realist epistemologies, whose core interest is in the subjective meaning rather than factual accuracy of data. However, comparison of familial report with clinician or administrative records may yield interesting insights on dynamics of communication and understanding. Objective psychopathological data would also help establish whether responses to diagnostic shifts differ according to the clinical validity of diagnostic decisions, and related effectiveness of treatment pathways. Finally, the study's inclusion of a wide range of diagnoses means findings are broad and heterogeneous: more granular research on specific diagnostic trajectories is necessary to identify the variables that predict more positive or negative outcomes. This study suggests that the expectedness of the change, treatment/service implications and diagnosis-specific stigma may modulate adaptation to diagnostic shifts; these dimensions represent productive foci for further research.

As the first study of the lived experience of diagnostic shifts, the current research raises important implications. A diagnostic shift is not mere change of nomenclature; it carries significant emotional, social and practical repercussions. The child and adolescent mental health field may benefit from a debate regarding the degree these pragmatic considerations should influence diagnostic decisions. While diagnostic shifts may threaten the therapeutic relationship and service-user understanding, they also offer an opportunity to enhance young

people's self-concept, social relationships and therapeutic engagement. Awareness of the socio-emotional ripple-effects that diagnostic shifts may trigger is vital to inform the sensitive communication and support approaches necessary to capitalise on these opportunities.

Ethics statement: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki declaration and its later amendments. The study was approved by University College Dublin's Human Research Ethics Committee, ref LS-17-105-OConnor-McNicholas.

References

Ahern, K. (2000). 'Something is Wrong with My Child': A Phenomenological Account of a Search for a Diagnosis. *Early Education and Development, 11*(2), 187–201. https://doi.org/10.1207/s15566935eed1102_4

Allsopp, K., & Kinderman, P. (2019). The use of diagnoses in mental health service eligibility and exclusion criteria. *Journal of Mental Health*. https://doi.org/10.1080/09638237.2019.1677875

Angermeyer, M. C., & Dietrich, S. (2006). Public beliefs about and attitudes towards people with mental illness: A review of population studies. *Acta Psychiatrica Scandinavica, 113*(3), 163–179. https://doi.org/10.1111/j.1600-0447.2005.00699.x

Batzle, C. S., Weyandt, L. L., Janusis, G. M., & DeVietti, T. L. (2010). Potential impact of ADHD with stimulant medication label on teacher expectations. *Journal of Attention Disorders, 14*(2), 157–166. https://doi.org/10.1177/1087054709347178

Bauer, M. W., & Aarts, B. (2000). Corpus construction: A principle for qualitative data collection. In M. W. Bauer & G. Gaskell (Eds.), *Qualitative Researching with Text, Image and Sound: A Practical Handbook* (pp. 19–37). Sage.

Bhugra, D., Tasman, A., Pathare, S., Priebe, S., Smith, S., Torous, J., Arbuckle, M. R., Langford, A., Alarcón, R. D., Chiu, H. F. K., First, M. B., Kay, J., Sunkel, C., Thapar, A., Udomratn, P., Baingana, F. K., Kestel, D., Ng, R. M. K., Patel, A., … Ventriglio, A. (2017). The WPA-Lancet Psychiatry Commission on the Future of Psychiatry. *The Lancet Psychiatry*, *4*(10), 775–818. https://doi.org/10.1016/S2215-0366(17)30333-4

Blázquez, A., Ortiz, A. E., Castro-Fornieles, J., Morer, A., Baeza, I., Martínez, E., & Lázaro, L. (2019). Five-year diagnostic stability among adolescents in an inpatient psychiatric unit. *Comprehensive Psychiatry*, *89*, 33–39. https://doi.org/10.1016/j.comppsych.2018.11.011

Boyle, M., & Johnstone, L. (2014). Alternatives to psychiatric diagnosis. *The Lancet Psychiatry*, *1*(6), 409–411. https://doi.org/10.1016/S2215-0366(14)70359-1

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research*. SAGE.

Braun, V., & Clarke, V. (2019). Novel insights into patients' life-worlds: The value of qualitative research. *The Lancet Psychiatry*, *6*(9), 720–721. https://doi.org/10.1016/S2215-0366(19)30296-2

Burke, J. D., Loeber, R., Lahey, B. B., & Rathouz, P. J. (2005). Developmental transitions among affective and behavioral disorders in adolescent boys. *Journal of Child Psychology and Psychiatry*, *46*(11), 1200–1210. https://doi.org/10.1111/j.1469-7610.2005.00422.x

Cooper, J. E., & Sartorius, N. (2013). *A companion to the classification of mental disorders*. Oxford University Press.

Copeland, W. E., Adair, C. E., Smetanin, P., Stiff, D., Briante, C., Colman, I., Fergusson, D., Horwood, J., Poulton, R., Costello, E. J., & Angold, A. (2013). Diagnostic transitions from childhood to adolescence to early adulthood. *Journal of Child Psychology and Psychiatry*, *54*(7), 791–799. https://doi.org/10.1111/jcpp.12062

Costello, E. J., Mustillo, S., Erkanli, A., Keeler, G., & Angold, A. (2003). Prevalence and development of psychiatric disorders in childhood and adolescence. *Archives of General Psychiatry*, *60*(8), 837–844. https://doi.org/10.1001/archpsyc.60.8.837

Craddock, N., & Mynors-Wallis, L. (2014). Psychiatric diagnosis: Impersonal, imperfect and important. *The British Journal of Psychiatry*, *204*(2), 93–95. https://doi.org/10.1192/bjp.bp.113.133090

Elkington, K. S., Hackler, D., McKinnon, K., Borges, C., Wright, E. R., & Wainberg, M. L. (2012). Perceived Mental Illness Stigma Among Youth in Psychiatric Outpatient Treatment. *Journal of Adolescent Research*, *27*(2), 290–317. https://doi.org/10.1177/0743558411409931

Ford, T., Macdiarmid, F., Russell, A. E., Racey, D., & Goodman, R. (2017). The predictors of persistent DSM-IV disorders in 3-year follow-ups of the British Child and Adolescent Mental Health Surveys 1999 and 2004. *Psychological Medicine*, *47*(6), 1126–1137. https://doi.org/10.1017/S0033291716003214

Freedman, R., Lewis, D. A., Michels, R., Pine, D. S., Schultz, S. K., Tamminga, C. A., Gabbard, G. O., Gau, S. S.-F., Javitt, D. C., Oquendo, M. A., Shrout, P. E., Vieta, E., & Yager, J. (2013). The Initial Field Trials of DSM-5: New Blooms and Old Thorns. *American Journal of Psychiatry*, *170*(1), 1–5. https://doi.org/10.1176/appi.ajp.2012.12091189

Halpin, M. (2016). The DSM and Professional Practice: Research, Clinical, and Institutional Perspectives. *Journal of Health and Social Behavior*, *57*(2), 153–167. https://doi.org/10.1177/0022146516645637

Hollway, W., & Jefferson, T. (2013). *Doing qualitative research differently: A psychosocial approach* (2nd ed.). SAGE.

Huws, J. C., & Jones, R. S. P. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability*, *33*(2), 99–107. https://doi.org/10.1080/13668250802010394

Joffe, H. (2012). Thematic analysis. In D. Harper & A. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: An Introduction for Students and Practitioners* (pp. 209–223). Wiley-Blackwell.

Joffe, H., & Yardley, L. (2003). Content and thematic analysis. In D. F. Marks & L. Yardley (Eds.), *Research Methods for Clinical and Health Psychology* (pp. 56–68). Sage.

Jones, J. L., Gallus, K. L., Viering, K. L., & Oseland, L. M. (2015). 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses. *Disability & Society*, *30*(10), 1490–1504. https://doi.org/10.1080/09687599.2015.1108902

Jovchelovitch, S., & Bauer, M. W. (2000). Narrative interviewing. In Martin W. Bauer & G. Gaskell (Eds.), *Qualitative researching with text, image and sound: A practical handbook.* (pp. 57–74). Sage.

Jutel, A. (2019). *Diagnosis: Truths and Tales*. University of Toronto Press.

Kerin, L. (2014). *National & international literature Review of good practice in child & adolescent mental health services*. Mental Health Reform.

Kim-Cohen, J., Caspi, A., Moffitt, T. E., Harrington, H., Milne, B. J., & Poulton, R. (2003). Prior Juvenile Diagnoses in Adults With Mental Disorder: Developmental Follow-Back of a Prospective-Longitudinal Cohort. *Archives of General Psychiatry*, *60*(7), 709–717. https://doi.org/10.1001/archpsyc.60.7.709

Kotov, R., Krueger, R. F., & Watson, D. (2018). A paradigm shift in psychiatric classification: The Hierarchical Taxonomy Of Psychopathology (HiTOP). *World Psychiatry*, *17*(24–25). https://doi.org/10.1002/wps.20478

Kranke, D. A., Floersch, J., Kranke, B. O., & Munson, M. R. (2011). A qualitative investigation of self-stigma among adolescents taking psychiatric medication. *Psychiatric Services*, *62*(8), 893–899. https://doi.org/10.1176/appi.ps.62.8.893

Kranke, D. A., Floersch, J., Townsend, L., & Munson, M. (2010). Stigma experience among adolescents taking psychiatric medication. *Children and Youth Services Review*, *32*(4), 496–505. https://doi.org/10.1016/j.childyouth.2009.11.002

Lahey, B. B., Loeber, R., Burke, J., Rathouz, P. J., & McBurnett, K. (2002). Waxing and waning in concert: Dynamic comorbidity of conduct disorder with other disruptive and emotional problems over 7 years among clinic-referred boys. *Journal of Abnormal Psychology*, *111*(4), 556–567.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, *33*(1), 159–174.

Leavey, J. E. (2005). Youth experiences of living with mental health problems: Emergence, loss, adaptation and recovery (ELAR). *Canadian Journal of Community Mental Health*, *24*(2), 109–126.

McGorry, P., & Nelson, B. (2016). Why We Need a Transdiagnostic Staging Approach to Emerging Psychopathology, Early Diagnosis, and Treatment. *JAMA Psychiatry*, *73*(3), 191–192. https://doi.org/10.1001/jamapsychiatry.2015.2868

Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder. *Sociology of Health & Illness*, *37*(2), 255–269. https://doi.org/10.1111/1467-9566.12208

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine: Journal of the Association of American Medical Colleges*, *89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388

O'Connor, C., Burke, J., & Rooney, B. (2019). Diagnostic disclosure and social marginalisation of adults with ASD: Is there a relationship and what mediates it? *Journal of Autism & Developmental Disorders*. https://doi.org/10.1007/s10803-019-04239-y

O'Connor, C., Downs, J., McNicholas, F., Cross, L., & Shetty, H. (2020). Documenting diagnosis in child and adolescent mental healthcare: A content analysis of diagnostic statements in a psychiatric case register. *Children and Youth Services Review*, *113*, 1-13. https://doi.org/10.1016/j.childyouth.2020.104948

O'Connor, C., Downs, J., Shetty, H., & McNicholas, F. (2019). Diagnostic trajectories in child and adolescent mental health services: Exploring the prevalence and patterns of diagnostic adjustments in an electronic mental health case register. *European Child & Adolescent Psychiatry*. https://doi.org/10.1007/s00787-019-01428-z

O'Connor, C., & Joffe, H. (2020). Intercoder reliability in qualitative research: Debates and practical guidelines. *International Journal of Qualitative Methods*. https://doi.org/10.1177/1609406919899220

O'Connor, C., Kadianaki, I., Maunder, K., & McNicholas, F. (2018). How does psychiatric diagnosis affect young people's sense of self and social identity? A systematic review

and synthesis of the qualitative literature. *Social Science & Medicine*, *212*, 94–119. https://dx.doi.org/10.1016/j.socscimed.2018.07.011

Ohan, J. L., Visser, T. A. W., Moss, R. G., & Allen, N. B. (2013). Parents' stigmatizing attitudes toward psychiatric labels for ADHD and depression. *Psychiatric Services*, *64*(12), 1270–1273. https://doi.org/10.1176/appi.ps.201200578

Palinkas, L. A. (2014). Qualitative and Mixed Methods in Mental Health Services and Implementation Research. *Journal of Clinical Child & Adolescent Psychology*, *43*(6), 851–861. https://doi.org/10.1080/15374416.2014.910791

Perkins, A., Ridler, J., Browes, D., Peryer, G., Notley, C., & Hackmann, C. (2018). Experiencing mental health diagnosis: A systematic review of service user, clinician, and carer perspectives across clinical settings. *The Lancet Psychiatry*, *5*(9), 747–764. https://doi.org/10.1016/S2215-0366(18)30095-6

Pettit, J. W., Morgan, S., & Paukert, A. L. (2005). The Stability of Axis I Diagnoses in Youth Across Multiple Psychiatric Hospitalizations. *Child Psychiatry and Human Development*, *36*(1), 53–71. https://doi.org/10.1007/s10578-004-3493-6

Rost, K., Smith, G. R., Matthews, D. B., & Guise, B. (1994). The Deliberate Misdiagnosis of Major Depression in Primary Care. *Archives of Family Medicine*, *3*(4), 333. https://doi.org/10.1001/archfami.1994.01850170047019

Ruble, L. A., Heflinger, C. A., Renfrew, J. W., & Saunders, R. C. (2005). Access and service use by children with autism spectrum disorders in Medicaid Managed Care. *Journal of Autism and Developmental Disorders*, *35*(1), 3–13. https://doi.org/10.1007/s10803-004-1026-6

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry*, *17*(2), 229–245. https://doi.org/10.1177/1359104510365203

Sasson, N. J., & Morrison, K. E. (2019). First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism*, *23*(1), 50–59. https://doi.org/10.1177/1362361317729526

Singh, I. (2003). Boys will be boys: Fathers' perspectives on ADHD symptoms, diagnosis, and drug treatment. *Harvard Review of Psychiatry*, *11*(6), 308–316.

Singh, I. (2004). Doing their jobs: Mothering with Ritalin in a culture of mother-blame. *Social Science & Medicine*, *59*(6), 1193–1205. https://doi.org/10.1016/j.socscimed.2004.01.011

Singh, I. (2011). A disorder of anger and aggression: Children's perspectives on attention deficit/hyperactivity disorder in the UK. *Social Science & Medicine*, *73*(6), 889–896. https://doi.org/10.1016/j.socscimed.2011.03.049

Skellern, C., Schluter, P., & McDowell, M. (2005). From complexity to category: Responding to diagnostic uncertainties of autistic spectrum disorders. *Journal of Paediatrics and Child Health*, *41*(8), 407–412. https://doi.org/10.1111/j.1440-1754.2005.00634.x

Southam-Gerow, M. A., & Dorsey, S. (2014). Qualitative and Mixed Methods Research in Dissemination and Implementation Science: Introduction to the Special Issue. *Journal of Clinical Child & Adolescent Psychology*, *43*(6), 845–850. https://doi.org/10.1080/15374416.2014.930690

Stephan, K. E., Bach, D. R., Fletcher, P. C., Flint, J., Frank, M. J., Friston, K. J., Heinz, A., Huys, Q. J. M., Owen, M. J., Binder, E. B., Dayan, P., Johnstone, E. C., Meyer-Lindenberg, A., Montague, P. R., Schnyder, U., Wang, X.-J., & Breakspear, M. (2016). Charting the landscape of priority problems in psychiatry, part 1: Classification and diagnosis. *The Lancet Psychiatry*, *3*(1), 77–83. https://doi.org/10.1016/S2215-0366(15)00361-2

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*(148). https://doi.org/10.1186/s12874-018-0594-7

Whooley, O. (2010). Diagnostic ambivalence: Psychiatric workarounds and the Diagnostic and Statistical Manual of Mental Disorders. *Sociology of Health & Illness*, *32*(3), 452–469. https://doi.org/10.1111/j.1467-9566.2010.01230.x

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 235–251). SAGE.