

## Chapter 2

# To Be Well Is to Be Not Unwell: The New Battleground Inside Our Children's Heads

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**Abstract** A number of factors are thought to increase the risk of serious psychiatric disorder, including a family history of mental health issues and/or childhood trauma. As a result, some mental health advocates argue for a pre-emptive approach that includes the use of powerful anti-psychotic medication with young people considered at-risk of developing bipolar disorder or psychosis. This controversial approach is enabled and, at the same time, obscured by medical discourses that speak of promoting and maintaining youth “wellbeing”, however, there are inherent dangers both to the pre-emptive approach and in its positioning within the discourse of wellbeing. This chapter critically engages with these dangers by drawing on research with “at-risk” children and young people enrolled in special schools for disruptive behaviour. The stories told by these highly diagnosed and heavily medicated young people act as a cautionary tale to counter the increasingly common perception that pills and “Dr Phil’s” can cure social ills.

**Keywords** Medicalization • Disadvantage • Behaviour • Children and young people “at-risk”

## Introduction

*Mental health is a state of emotional and social wellbeing. It influences how an individual copes with the normal stresses of life and whether he or she can achieve his or her potential. Mental health describes the capacity of individuals and groups to interact, inclusively and equitably with one another and with their environment, in ways that promote subjective wellbeing and optimize opportunities for development and use of mental abilities.* (Australian Bureau of Statistics 2001, p. 4)

Wellbeing is a relatively recent and, as yet, still amorphous concept; one that is absently defined through vague references to mental health and its more sinister shadow, mental illness. Whether subtly or otherwise, the discourse of wellbeing is underpinned by an individual disease model and, as such, is inherently medical

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in concept. As a result, what it means to be “well” comes to be defined by the absence of psychiatric symptomatology or, in other words: to be well is to be not “unwell”. Although a family history of mental health issues and childhood trauma are known risk factors for developing mental disorders, the application of a medical lens to human emotional distress can lead to treatment responses that eclipse these influences and their impacts. In the race to develop treatments that can reach more patients and methods to identify untreated sufferers, natural human reactions to loss, disappointment, disrespect and even abuse have become symptoms of individual pathology, as opposed to indicators of disadvantage or injustice (Levine 1997).

A number of dangers present as a result. One danger is that children and young people are constructed as “unwell” when they may not be, and another is that they are subjected to individualized treatments when the real problem may well reside within their social context (Isaacs 2006). These are familiar dangers. Few would be unaware of the controversy surrounding Attention Deficit Hyperactivity Disorder (ADHD); a controversy that stems from the same two concerns (Graham 2010). One criticism of ADHD is that the diagnostic criteria are so broad that we risk medicalizing ordinary child behaviour (danger 1). Another is that behaviours stemming from hunger, abuse, neglect, tiredness, poor diet, inappropriate curriculum, inconsistent parenting and/or poor teaching may be misdiagnosed as neurological dysfunction and treated pharmacologically (danger 2). Although these are familiar issues, the dangers involved with mental health diagnosis and treatment have increased in recent years with the ascendance of biopsychiatry (Rose 2007), and an associated upwards trend in the use of psychopharmacological agents in the treatment of behavioural problems (Frances 2013).

This trend has a long history marked by at least two epochal turns. The first was the discovery of “hyperkinetic reaction of childhood” – one of at least five precursor categories to what is now called ADHD – and the rapid rise in the prescription of stimulants to difficult and disruptive children (Smith 2008). The second turn is related but less well known. It began in the 1990s when the self-proclaimed “god” of ADHD clinical research (Healy 2006), Professor Joseph Biederman, estimated that some 50 % of the children participating in his treatment studies had symptoms of what he believed was juvenile bipolar disorder. At the time the medical fraternity was shocked; prevailing opinion was that bipolar disorder arose in adolescence or adulthood (Healy 2006) and that the main symptoms – mania and depression – were *episodic*, not chronic (as per the symptoms of ADHD). Biederman and his colleagues, however, argued that childhood-onset BPD was different to adult BPD, in that it “appears to present with an atypical picture characterized by predominantly irritable mood, mania mixed with symptoms of major depression, and chronic as opposed to euphoric, biphasic, and episodic course” (Wozniak et al. 1995, p. 459).

Biederman (1998) further suggested that the core symptoms of ADHD – inattention, impulsivity and hyperactivity – were *predictive* of BPD which could be prevented with “prophylactic pharmacotherapy” (Biederman 1995, p. 229) that involved the pre-emptive use of highly restricted mood-stabilizers, such as lithium, or anti-psychotics, like Risperdal, in young children. By 2001, “more than

100,000 children were being medicated for BPD” in the United States, with “the percentage of children being clinically diagnosed more than doubling” by 2008 (Youngstrom et al. 2008 p. 2). Three years later Biederman was investigated and found to have violated the conflict of interest policies of both Harvard University and Massachusetts General Hospital by failing to report \$1.6 million in income earned from pharmaceutical companies (Kaplan 2011). Meanwhile, Johnson & Johnson has paid out billions to class action plaintiffs affected by Risperdal; the efficacy of which Biederman is alleged to have guaranteed to his funders prior to commencing clinical trials (Harris 2009).

Although the concept of childhood-onset bipolar disorder has since been displaced – and some might say, discredited – by the instantiation of a new diagnostic category, Disruptive Mood Dysregulation Disorder (DMDD) in the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the idea that treatment of “pre-symptoms” (that may signal the risk of future psychiatric illness in early adolescence or childhood) has spread. Take, for example, the recent and much criticized push for “pre-psychosis” intervention where young people “manifesting precursor signs and symptoms who have not yet met full criteria for diagnosis” (Mrazek and Haggerty 1994, p. 154) are treated pharmacologically with anti-psychotics, such as Seroquel and Risperdal, to “delay or even prevent onset of psychosis” (Jung and McGorry 2007, n.d.). Proponents pushed hard for the inclusion of “pre-psychosis risk syndrome” in the DSM-5, however, “given the expected high false positive rate and the unfavorable risk-benefit ratio” (Corcoran et al. 2010, p. 10), others urged caution.

While pre-psychosis risk syndrome did not make it into the final DSM-5, which was released in 2013, pre-psychosis treatment is still actively promoted and it still occurs. In Australia, for example, treatment with anti-psychotics for young people considered at-risk of developing psychosis has been advocated by *Orygen Youth Health* and the *Early Psychosis Prevention and Intervention Centre* (EPPIC) which was founded by Professor Patrick McGorry, the world’s leading proponent of pre-psychosis intervention. McGorry is associated with a number of networks and centres – including headspace, the Young and Well Cooperative Research Centre, and even the Centre for Music, Mind & Wellbeing – all of which refer to youth mental health and wellbeing as a core focus. Given the positioning of the pre-emptive approach within an otherwise benign and universal discourse that constructs “wellbeing” as a tenuous state of “being (not un)well”, there is a very real danger that children and young people who are living under difficult circumstances may be too quickly diagnosed and medicated for disorders that they do not yet (and may never actually) have.

As mental health diagnoses carry significant stigma and psychoactive medications can be neurotoxic, these dangers are serious enough. A third danger, however, and one that receives much less focus than it should, is that young people who face difficult circumstances may come to view themselves as mentally disordered; believing that their “illness” is both immutable and organic to them, not something that can be changed or addressed by way of improvement in other spheres of their

life. In this way, what currently *is* cements into what will always *be*: an intrinsic part of life for “someone like *me*”. A lack of belief in one’s ability to change one’s own behaviour and life circumstances is, fundamentally, to lack agency. As described by Albert Bandura (2006, p. 164):

[t]o be an agent is to influence intentionally one’s functioning and life circumstances. In this view, personal influence is part of the causal structure. People are self-organizing, proactive, self-regulating, and self-reflecting. They are not simply onlookers of their behaviour. They are contributors to their life circumstances, not just products of them.

Importantly, a sense of agency has been identified as one of three key elements to children’s wellbeing, in addition to a positive sense of self and feelings of security (Fattore et al. 2009; Foley et al. 2012). It is my contention, however, that all three of these elements – positive sense of self, feelings of security and a sense of agency – are eroded when young people are diagnosed, medicated and excluded from school, indicating an element of hypocrisy in the discursive co-option of the “wellbeing” discourse by proponents of pharmacological intervention.

Researchers considering the inclusion of psychosis risk syndrome in the DSM-5 came to the conclusion that this was a significant danger, arguing that being “labeled with severe mental illness has the potential to permeate one’s social identity and threaten a sense of normalcy” (Yang et al. 2010, p. 45). Further, given the developmental age of the young people in question, Yang and colleagues warned of two other implications for identity formation: first, “mental illness ‘labeling’ may interfere with the acquisition of ‘personal assets’ or competencies needed for successful passage to adulthood” (Yang et al. 2010, p. 45), and second, there is a risk that a young person’s self-concept will be “transformed via a process whereby illness roles become central to an individual’s identity and valued social roles diminish until only a ‘chronically ill’ role remains” (Yang et al. 2010, p. 45).

The self-fulfilling prophecy effects of mental health diagnoses have been raised in the critical literature with a number of researchers drawing on poststructural theories of discourse and power to consider the role of labelling in the production of mentally disordered subjectivities (see, for example, Harwood 2006). While I am sympathetic to such analyses and have used them previously to examine how fidgety, distractible children are constructed as behaviourally disordered (Graham 2008), here I am concerned with the effect of school exclusion, diagnosis and medication on young people’s sense of purpose and control over their own lives. Previously I have argued with respect to ADHD, that the fundamental difference between the medical and psychological models can be found in their respective theorization of agency, reason and control:

The medical model appears to accept “disordered” children as having little or no control over their actions. The psychological model, on the other hand, is dependent for its very existence on the assertion that the child *can* exert or *learn* self-control. (Graham 2008, p. 21)

In my earlier work, I argued that ADHD had effectively brokered an alliance between psychology and medicine because psychological interventions had so far failed to show superior effect over medication treatment when each were

taken alone.<sup>1</sup> This has led to a reciprocal relationship between the two fields – despite fundamental differences in perspective – with psychology forced to subordinate to the medical model in order to remain relevant in the treatment of difficult and disruptive children (Graham 2008). This uneasy alliance is epitomized in the “reach before you can teach” mantra which is used to justify the use of medication as a first-line response. Multi-modal treatment plans that have Cognitive Behavioural Therapy (CBT) following hard on the heels of medication are supposed to be the gold standard; the rationale being that medication will address deficits in executive function that lead to poor self-regulation (the “reach”), making it possible for children to then learn CBT strategies and to put them into place (the “teach”). The paradox however is that young people need agency to both want and to be able to achieve this but their capacity for agentive action is precisely what is at stake when they come to believe that they are in the grip of something that is more powerful than themselves; whether that be mental illness, medication, the adults in their lives, or the source of the problems they face.

These are the dangers of positioning mental (ill)health within a generic discourse of youth wellbeing. The first danger is that we risk medicalizing the reactions of young people living in distressing social circumstances. The second danger is that these young people may then be subjected to treatments that further individualize those issues, effacing broader social influences and their impacts. The third danger is that young people may come to know themselves as “disordered”, which can rob them of both the voice and agency they need to overcome the difficult circumstances they face. This chapter aims to critically engage with each of these dangers by analyzing data from a series of interviews with 25 children and young people who have been identified as behaviourally disordered and enrolled in special “behaviour” schools. These data suggest that children and young people who are living in distressed social circumstances *can* and *do* internalize medical diagnoses; believing both that there is something organically wrong with them and that there is little they can do to change their situation. While some may resist the construction of their self as “unwell”, overall their narratives suggest that the process of being diagnosed, medicated and enrolled in a special school is disabling for many.

## The Study

New South Wales (NSW) is Australia’s largest state comprising one third of the national population. The government school sector educates 66 % of the K-12 schooling population with over 2,200 schools and 744,392 students (Australian Bureau of Statistics 2011). The NSW government school sector also has the largest parallel special education system in Australia with over 2,000 support classes and

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<sup>1</sup>The MTA Longitudinal Treatment Study has since found that medication has no additive benefit over time – at 36 months all four groups performed equally (see discussion in Graham 2010).

113 special schools. These schools, termed “Schools for Specific Purposes” (SSPs), form the most restrictive placement option. Over the last two decades there has been a significant increase in their use, mainly due to growth in enrolments under the categories of emotional disturbance and behaviour disorder (Graham and Sweller 2011). Recent research has found that this increase coincided with the establishment of a series of separate “behaviour” schools (Graham et al. 2010), which now account for more than one third of all special schools in the NSW government schooling sector (Graham 2012). The overwhelming majority of these schools are located in disadvantaged communities. However, there is a lack of quality research to indicate what effect enrolment in a behaviour school has on the children involved or what contribution is made to their future educational success. Despite this gap in the research knowledge, the use of special schools and classes for students who engage in disruptive behaviour is growing, while the average age of the students who attend is decreasing (Graham et al. 2010). The aims of the study on which this chapter draws were to document how such interventions take form and the ways in which these are perceived by students and school personnel; trace student memories of their prior schooling experience and what connection, if any, these students make between these experiences and where they are now; track changes in student attitudes, beliefs and behaviour during and after their enrolment in special schools; and observe and analyze student re-integration to regular schooling to understand what events lead to positive and negative experiences (Graham et al. 2011).

To engage with these aims, the study utilized a cross-sectional mixed-method longitudinal research design (Creswell 2003; Takkashori and Teddlie 1998) with 96 participants aged between 9 and 16 years. The research participants were recruited in three groups from both mainstream and separate special educational settings; including 33 students currently enrolled in behaviour schools (the longitudinal group), 21 students with a history of severely disruptive behaviour still enrolled in mainstream schools, and 42 students enrolled in mainstream schools with no history of disruptive behaviour. The project was designed to progress in three phases. In Phase 1, each student participated in a semi-structured interview that was designed to tap into students’ perspectives on schooling, teachers and teaching; their self-perception and peer-relationships; experiences of change and dislocation; future aspirations; knowledge of diagnosis and medication; and memories of current and past schooling experiences. Phases 2 and 3 were scheduled at 6 monthly intervals to longitudinally follow-up with the 33 students in the behaviour school group and to gauge whether their perceptions or experiences changed over the ensuing 12 months.

The behaviour school group was recruited first from five participating case-study behaviour schools located in the greater Sydney metropolitan region. Three of the five schools were located in severely disadvantaged communities, one school in an area that would be considered disadvantaged and one from an economically advantaged area. This is reflected in each school’s score on the Index of Community Socio-Educational Advantage (ICSEA). However, as geographic information or single ICSEA scores could reveal the identity of the schools, only ICSEA ranges

**Table 2.1** Socio-educational background of participating behaviour schools

ICSEA range	Number of schools
1,100–1,200	0
1,001–1,099	1
Mean = 1,000	
900–999	1
800–899	3

have been provided here.<sup>2</sup> As shown in Table 2.1 above, two case-study behaviour schools received scores 2 standard deviations (SD) below the ICSEA mean, one was 1 SD below and one school was 1 SD above.

This chapter focuses on the interview responses of students in the behaviour school group who confirmed that they were currently taking medication or had taken medication in the past. Individual responses to structured questions such as “What is that medication for?” “Does it help?” “Do you experience any side-effects?” “How do you feel about taking medication?” were coded using inductive content analysis (Berg 2001) and are presented below using simple descriptive statistics. Open-ended prompts were issued to encourage participants to voice their perspectives and to further examine issues that were raised by the participants themselves. Examples are presented later in the chapter through two case studies developed from student, parent and school principal interviews, as well as ethnographic data obtained during the overall data collection process. These young people’s stories suggest a disturbing lack of consultation between medical practitioners, school practitioners and parents/caregivers at one end and young people on the other. The impacts of diagnosis and forced medication for young people’s agency and ability to pursue their own conception of “wellbeing” are discussed.

The Twenty Five

A total of 33 students enrolled in behaviour schools participated in interviews designed to track their school experiences. During the interview students were asked if they were taking any medication that they knew of. Nineteen responded that they were currently taking medication and six replied that they used to but had now discontinued. Each of these 25 students was then asked what type of medication they were or had been taking and if they knew what it was for. Five did not know the brand but some were able to describe the medication and/or indicate what it was

<sup>2</sup>The Australian government has allocated every school in Australia with a score on the Index of Community Socio-educational Advantage based on parent occupation, educational level and achievement, and school characteristics including remoteness and percentage of Indigenous students. ICSEA has a mean of 1,000 and a standard deviation of 100.

for. While some simply referred to “ADHD” or “sleeping” tablets, the remaining 16 students were able to identify the brand and some even noted the milligrams; e.g., Ritalin 10 or Ritalin 40 (see Table 2.2 below).

Not surprisingly, stimulants were the highest prescribed medication type (15 students), followed by anti-depressants (5), anti-coagulants (2) and lastly, anti-psychotics (2). More than one third of these young people either was or had been taking more than one medication concurrently, with one student taking five highly restricted medications daily.

When describing what the medication was for only nine students referred to a diagnosed condition. Attention Deficit Hyperactivity Disorder (ADHD) was the primary diagnosis offered by these nine students, three of whom also nominated Oppositional Defiance Disorder (ODD). However, there was considerable confusion in relation to diagnosis. One student, for example, named “ADHD, ODD, ADOD . . . (pause) and something else” (Cameron, age 13). Another student differentiated between his mental health diagnoses by saying that one of his medications was to treat “ADD and ODD” and the other was to treat “ADHD or something” (Adam, age 14). The remaining students referred to personal, emotional and behavioural characteristics, such as “attitude” (Oliver, age 13) and “anger” (Andy, 12) to explain why they were taking medication with a number then referring to school:

To try and make me act better at school. (Harry, 11)  
So I’m not bad at school. (Jack, 11)

Follow-up prompts were issued to gauge whether these young people experienced any medication side effects, whether they felt that medication was helpful to them, and how they felt about taking it. Appetite suppression, weight loss and sleep deprivation were the most common. Despite students in the behaviour school registering expressive vocabulary scores that averaged one standard deviation below the mean, these young people were very articulate when it came to describing medication side effects, particularly on the issue of depleted energy and physical strength:

At the start it makes you feel sick. Like you got a headache and a stomach ache and that. And then it makes you just, like, it makes you feel like you got a lot of energy but when you start runnin’ around, it’s like you got no energy. (John, 13)

I don’t feel hungry. I’m weak, so if someone – if I get into a fight or something, they’re going to beat me because I’m weak. (Cameron, 13)

I don’t feel hunger. I only feel the pain of not eating. There is no such thing as . . . there is NO hunger. There is only like I can put food in to stop the pain but it’ll probably either get thrown back up or make it worse. I’ll go through a whole day and at the end of the day I’ll go oh what the fuck is this and I’ll be like oh my God I haven’t eaten today. (Ethan, 13)

When asked if the medication helped, responses were mixed. Just over one third stated that their tablets *did* help, five either didn’t respond or said “dunno”, while almost half said the medication did not help.



Table 2.2 Number and types of medications reported

Pseudonym	Age	Taking/ discontinued?	Type? “dunno”	Stimulant	Anti-psychotic	Anti-depressant	Anti-coagulant	Other
Zack	12	Yes		Concerta	Risperdal			
Ethan	13	Yes		Concerta (Dex & Ritalin, discontinued)				
Oliver	9			Ritalin				
Andy	12	Yes	X					
Ziggy	13	Yes						Melatonin
John	13	Discontinued	X					
Cameron	13	Yes	X					
Max	13	Yes		Ritalin	Seroquel	Endep	Catapres	Sodium valproate Sleeping tablets
Tom	12	Yes						
Grant	12	Discontinued		Ritalin				
Nathan	13	Discontinued						ADHD tablets
Cooper	16	Yes				“Anti-depressants”		
Darrin	12	Yes		Concerta				
Quade	16	Discontinued						A white one & a purple one
Owen	12	Discontinued		Dex-amphetamine				
George	15	Yes		Ritalin & concerta				
Harry	11	Yes		Ritalin (discontinued)		Endep		
Liam	13	Discontinued	X					
Jack	11	Yes		Ritalin 40				
James	11	Yes		Ritalin 40				

(continued)

Table 2.2 (continued)

Pseudonym	Age	Taking/ discontinued?	Type? “dumbo”	Stimulant	Anti-psychotic	Anti-depressant	Anti-coagulant	Other
Reuben	12	Yes		Concerta		Lovan		
Michael	14	Yes					Catapres	“... and something else to sleep”
Rory	13	Yes		Concerta 36 & Ritalin				
Adam	14	Yes		Concerta		Lovan		
Patrick	10	Yes		Ritalin 10				
25 students	Avg. age: 12.6	19 currently	16 %	60 %	8 %	25 %	14 %	14 %
		6 discontinued						

It calms me down. And I'm very quiet when I have it. [If I didn't take it] I would get all agitated and say some funny things, or I wouldn't do my work. I'd get bored of this [the interview]. (Patrick, age 10)

Yeah, it does. It helps me with me work. It helps settle me down. Doesn't make me so, um . . . crazy. Making people laugh and just being silly. (Darrin, age 12)

It made me 10 times worse . . . Mum chucked it down the toilet. (Grant, age 12)

It was not doin' nothin' but making me feel shit. (Quade, age 16)

Importantly, even though 9 of the 25 said that the tablets *did* help, only three out of those nine were positive when asked how they felt about taking medication. The rest expressed a desire to stop:

I don't want to take tablets. I want to be like a normal kid. (Jack, age 11)

I don't like it because I don't talk to no-one or anything. I'm like in zombie mode so I just don't have it. (Adam, age 14)

I didn't want to because it makes me really skinny. It stops me eating. I used to look like a junkie. (Owen, age 12)

One common theme among the students who had been prescribed medication was a perceived lack of voice in decision-making with a number saying that they would "chuck it in the bin" (Zack, age 12) or find other ways to avoid taking them without their parent's or school's knowledge. These themes were investigated in more detail in the second round of interviews with questions designed to probe the diagnostic process, including whose suggestion it was to seek medical advice. Their stories reveal little consultation at point of diagnosis and/or prescription and, in some cases students noted that their school had barred attendance unless they were medicated:

The principal at [my old school suggested]. They said if he's not put on medication by next week, because I got a week's suspension, I wasn't allowed to go back to school. They were going to expel me, so they [the doctor and my mum] put me on it. (Cameron, age 13)

If I could stop I would but I wouldn't get any schoolwork done. They're not going to let me stay at this school unless I do take my meds. That's actually a contract that I signed on; that I won't come to school unless I'm on some of my meds. (Ethan, 13)

. . . the school suggested [to] my mum that I should take medication for my subjects, to see if I've got ADHD . . . One tablet would put me to sleep – which they – the school wanted my mum to keep taking – giving me them ones, because it's good for them when I went to sleep at school . . . They were happy with that. My mum wasn't because she wanted me to get help. [*Why were they happy that you were asleep?*] Because I wasn't annoying anyone or I wasn't having bad behaviour. I was just sleeping all day. (Owen, 12)

By the time we returned to conduct the second interview 6 months later, 6 of the 25 had either aged out of school or were impossible to track down due to chronic absenteeism. When asked what would make them happy in life, 3 of the remaining 19 behaviour school participants answered "dunno" or "nothin". The last 16 expressed fairly simple wishes that revolved around four main themes: (1) friends,

family and love, (2) gainful and satisfying employment, (3) security, and importantly, (4) personal autonomy:

Just doin' things *I* like to do. (Zack, 12)

Having a wife and kids and doing my own thing. (Nathan, 13)

Get all the stuff *I* want. Have, like, two magic fairies, I don't know, so whenever I say "I wish" it comes true or something. [*What would you wish for?*] Get out of school! (Grant, 12)

This last theme is an important consideration given the lack of autonomy experienced by these young people, particularly given that their lack of voice in decision-making was not restricted to medication. Most students were unsure of how long they would be in the behaviour school or what they had to do to be able to return to regular schooling. However, as discussed in the introduction to this chapter, lack of voice and personal autonomy in decision-making about one's own life is not conducive to producing the conditions of possibility required for the development of agency; an ability that is necessary for young people to successfully negotiate and overcome difficult circumstances.

In the following section, I present two case-studies drawn from interview and ethnographic data collected over an 18 month period to illustrate how experiences of diagnosis, medication and exclusion manifest in young people's beliefs about themselves and their ability to positively affect and direct their own lives. It is important to note that the experiences described here were not limited to the young people that have been selected for discussion, nor were they limited to students enrolled in behaviour schools. Indeed, as noted by one of the principals of the participating behaviour schools, "there is not a crack of daylight between who gets into our school and who is 15th in line" (School 3). Similar stories were relayed by other students with a history of disruptive behaviour, including those enrolled in mainstream schools, the only real exception being students from schools in highly-advantaged areas whose parents were more able to act as advocates for them and students whose parents actively resisted any pathologization of their child.

## Catch-22

Zack's was the first participant consent form to arrive in the mail. Included with the consent form was the Achenbach Child Behaviour Check List – Parent Report Form, which had been completed by his grandmother. Zack had been in her care since he was 2 years old after suffering abuse at the hands of his mother and her then boyfriend who was unrelated to Zack. His father's occupation had been listed as "jail and drugs" and his mother's as "smoking pot and stealing shop". He was 12 when I first met him.

Zack moved slowly into the interview room. He was overweight for his age and wore glasses. The behaviour school principal had mentioned that he was one of

a number of “refugees from the mainstream” who had been sent to the behaviour school not because they were violent thugs but because they were small and “odd” and thus the target of school bullies. Due to the culture in some of the mainstream schools from which we drew our participants, Zack had learned, as reported by many of the behaviour school kids: “to bash or be bashed”. Typically though, he would come off second best. Because he couldn’t outrun and he couldn’t fight back, all he had at his disposal was tough talk and public acts of rebellion for which he was now paying the price.

Twelve year old Zack reported that he had been taking Risperdal (an anti-psychotic) and Concerta (a long-acting stimulant) for about 6 years but “I don’t know what they are. I don’t know what I take them for.” When asked if they helped, he said “Nup”. In our second interview, he confirmed that he was still taking Concerta and Risperdal and that he was taking them for “behaviour and depression” but “I dunno *why*”. Later when he was asked if the medication helped, he said “Nuh. Don’t even – not even depressed!” He argued that the medication made no difference because “I used to never take it; I used to chuck it in the bin.” One of the side effects he noted was that the Risperdal made him eat a lot.<sup>3</sup>

Zack reported that these two medications had been prescribed by two different doctors, one of whom believed the Risperdal – an S4 restricted drug requiring Australian federal government authority to prescribe – was not helping.

She wants to take me off it. She has to ring up the other paediatrician that gave it to me. She told me I have to get off it and she’ll try and get me off it if she can.

Zack had no idea how or when this would happen but he said that when he had told his grandmother and the other paediatrician that he wanted to stop medication, they had told him he had to “prove himself” before he would be allowed to discontinue. Earlier in the interview, Zack used the same term when talking about getting a “second chance” through the behaviour school and how that related to re-integration to mainstream:

You’d be good here for a while and then they start thinking about sending you to a different school for like a day or something . . . a day each week. Prove yourself. If you prove yourself, you go there full time.

Zack’s words “they start thinking” betray his lack of voice and agency. Rather than describe a plan for action – *change your behaviour here and then you will be able to return to mainstream through partial re-integration* – he is told to prove himself first and “then *they*’ll think about it”. When asked if he had ever attempted partial re-integration, Zack said he had but that he had been “stopped from going” – an interesting choice of words in itself – because he had not gone to class on the 1 day a week that he was allowed to attend a mainstream high school. His reason for avoiding class was that he couldn’t engage with the level of work nor could he navigate a foreign high school campus; something that had been noted as a

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<sup>3</sup>Significant weight gain is a known side effect of Risperdal (Parikh et al. 2008).

common problem affecting re-integration by all five participating behaviour school principals:

... high schools have 75 or 80 minute periods. They have an A week and a B week. So in this week if a kid goes back on a Thursday, he hits English, Maths, Science, Art. He goes back the next Thursday, he hits four different subjects. Then it's a fortnight in between ... at the same time everybody else in the class is hitting that lesson three other times. So our kid is expected to be up-to-date. Teachers have 200 kids to teach – are they supposed to remember that student actually wasn't there the last three classes and cut him a break? They don't. (Principal, School 2)

Now 14, Zack is resigned to remaining in the behaviour school, where he now prefers to be anyway. His reason for not attempting to reintegrate after 3 years in the behaviour school is that he has “spent too much time here” and that he “won't mix well at another school”. He reasons that with only another year and a half of school to go before he can leave to train at TAFE to achieve his dream of becoming a reptile handler, there is no point in trying.

Paradoxically, however, Zack is still being told to “prove himself” before he is allowed to stop taking anti-psychotic and long-acting stimulant medication from which he suffers side-effects and that he and one of his doctors do not believe is helpful. The only way that he can prove himself is to successfully return part-time to an unyielding and unresponsive secondary school system that has proven unable or unwilling to support the integration of students from behaviour schools. Zack is therefore caught in a proverbial Catch-22, constructed as unwell when he believes he is not but without any way of proving himself otherwise. While Zack has thus far been able to resist fully internalizing this construction, others have not fared so well.

## Boy Interrupted

Max was a 13 year old “school refuser” whose mother called to request that we see him at home where she felt that he would feel safer talking about his school experiences. He lived in a public housing estate in a disadvantaged area of Sydney and, while Max had been referred to a behaviour school for violence, the school advised that this was mainly directed at school bullies and that it should be safe for adults to visit him at home. As university research safety policy requires that two researchers attend home visits to potentially dangerous locations, my research assistant and I met at the address provided. When we walked up the drive to the entrance of the little semi-detached villa, someone darted from one of the chairs outside the door and into the neighbouring villa. The pungent aroma of marijuana greeted us at the doorway.

Undaunted, we rang the bell and Max's mum opened the door. She was bubbly, friendly and completely lucid. She welcomed us into a small living room and called Max. It was dark inside the house with blinds covering the windows and it took some time for our eyes to adjust. The only light was emanating from a computer

screen tucked away in the corner of the room. Hunched in front of it was a pale skinned, blonde haired boy who seemed oblivious to our presence. His mum asked if we would like a cup of tea while we set ourselves up on the dining table. She seemed anxious to talk and grateful that someone was interested in learning more about her child. Max continued to ignore us.

Eventually his mother managed to coax him away from the computer and Max approached the table. He was surprisingly tall once he uncurled himself from the little computer chair and very lean but well-built and strong looking. We cheerfully introduced ourselves, explained the research, asked if he consented to participate, and showed him the Peabody Picture Vocabulary Test (PPVT) as an example of what we were going to do in the session. Max nodded and signed the consent form but seemed barely conscious. When he did look at us, he did so by leaning his head back, so that he could see through half-open eyes. His speech was slow and slurred, which prompted his mother to explain that she'd "upped" his medication in anticipation of our visit.

In all four of our meetings and all three interviews, Max was guarded. He would consider questions deeply before answering them and, if they were what *he* considered personal or potentially straying near a topic he did not want to talk about, he would politely decline to answer. For example, the first time he encountered the State/Trait Anxiety Inventory, he declined to participate as he deemed questions about emotions too personal. Max also had an issue with the same interview questions being asked of all participants as he believed he was "different" and he did not see how structured questions could capture *his* story. In response to questions about medication, he replied:

See, the problem is one person asked me half of these questions once and then my mum got really angry at them because they were asking personal questions about me and they had no right to know before I went to their school . . . I just don't know any more if anyone's allowed to be asking these questions at all . . . I don't really want to answer anything about the tablets. (Max, age 13)

As we also had ethics clearance to speak to parents, I invited Max's mother, Julia, to participate in an interview to provide us with some background knowledge of Max.<sup>4</sup> She was very happy to participate and to discuss diagnosis and medication.

During her interview, Julia revealed that Max was on five concurrent medications: Seroquel (an anti-psychotic), Endep (a tricyclic anti-depressant often used with children diagnosed with ADHD), Ritalin (a stimulant), Catapres (an anti-coagulant typically used to treat hypertension but also used off-label to treat ADHD), and sodium valproate (an anti-convulsant typically used to treat epilepsy but also used off-label for children with autism). Seroquel, she explained, had been added when Max was admitted to the Child and Adolescent Psychiatric Unit at the Children's Hospital (aged 11) but that he had been on a variety of medications since he was diagnosed with ADHD in preschool.

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<sup>4</sup>Funding for parent and principal interviews was provided by Macquarie University's Concentrations of Research Excellence (CoRE) program.

In the years following preschool, Max acquired three more diagnoses, including Oppositional Defiance Disorder, anxiety and Asperger's Syndrome. Both his mother and the head of the support unit he was now attending noted that the autism diagnosis was a means to find a placement. Julia explained that she'd had to learn to "work the system", even going so far as to move to Sydney and relinquish care to the Department of Community Services (DoCS) to get the support she needed:

The amount of guilt and crap I went through, it was just unbelievable. But he managed, after that . . . 'coz from Redbank they were trying to get him a place at Hall Ward, which is a children's lock down mental health unit at Westmead Children's and they said no beds, no beds, but the day I put him into DoCS care there was a bed.

The head of the support unit Max was attending was of the view that he was emotionally disturbed but not autistic and that the Autism Spectrum Disorder (ASD) diagnosis had been signed off to ensure a place in a support setting. According to this teacher, Max and his mother had issues with co-dependency and much of the school's effort was focused on helping Max make it through a full day without requesting to be picked up by his mother. Julia herself acknowledged that this was an issue and attributed it to their being a single-mother/only-child dyad. However, her story indicates that there were contributing factors beyond their relationship.

Julia explained that while she had now turned her life around and was studying at university, Max's early life had been extremely traumatic with his parents splitting up when he was a toddler:

I found out [Max's father] been smoking heroin and was doing break and enters to support his habit, and then he finally got caught with a couple of friends, breaking into a Retrovision store. Went to jail for 12 months. I waited, I did the weekend visits and the money in the account, and I worked a night time job to support him and us and wrote letters every day, and made sure I was there for phone calls and all the rest of it. Then he came out and then two months later I found dirty needles in my garage. So I call the police and . . . he spent the next two years in and out of jail, and . . . well, when I went for custody, he was actually incarcerated. Had the option to come to the courthouse but decided he wasn't going to come because he wouldn't have won anyway.

Julia reported that neither she nor Max had received counselling in those critical early years despite the presence of acknowledged "risk-factors". Max began acting out in preschool and was soon diagnosed and medicated for ADHD. By Year 3, he began moving from school to school and Julia said that for the first 5 years of his schooling life, Max would have been lucky to spend more than two hours a day at school before they would call her to tell her to come and pick him up for misbehaviour. After he was diagnosed with Asperger's Syndrome and placed in a support unit in country New South Wales, it was a little easier to keep him at school; however, Max's anger then began to be directed towards her:

Then we got to a stage where Max was actually beating the crap out of me. It was really bad for about 12 months. I started drinking and just not wanting to deal with him at all. I didn't even want to look at him. Didn't want to speak to him. I just . . . I'd had enough.

And so, Julia relinquished care to DoCs and Max was placed on Seroquel in addition to the four other medications he had already been prescribed. In his words, he is in the special class:



...because I have autism and showed bad signs when I was little... No-one likes me, everyone hates me. After a while you can't just take it all up and move all the time, so I just decided to punch my way out of it... It's working now. Everyone that doesn't want to get hit leaves me the hell alone. (Max, age 13)

Max is a quirky individual and there are hints of ASD characteristics, such as obsessive interests (medieval history, chess and Xbox Live) and preference for rules, however, in my view it would still be a stretch to diagnose him with autism. Max makes eye contact, does not engage in self-stimulatory behaviour, does not speak in monotone and is oppositional in the face of something he would prefer not to do, rather than hysterical. While his seclusion at home and in separate settings may have accentuated his eccentricities, Max is functionally capable and could – with consistency in support and guidance – draw on his intellect to make his way in the world. This appears an unlikely prospect now, however, as Max is convinced otherwise. While he states that the purpose of school – or at least the schools that he knows – is to help him develop something resembling a sense of agency and a sense of autonomy, he does not appear to believe that this is possible for someone like him.

Interviewer: What do you think school is for?  
 Max: To learn how to do things right for when you grow up, so you can handle yourself.  
 Interviewer: I see, yep, and is that important to you?  
 Max: No.  
 Interviewer: Why not?  
 Max: Cause you know I'm screwed.  
 Interviewer: Yeah?  
 Max: I've had a shit amount of time at school, I'm bad at everything, no, yeah, so I don't really care anymore.

Max was not the only 1 of the 25 to have internalized his diagnosis or difference as an immutable part of his self. The majority either attributed their being sent to the behaviour school or their difficulty at school to something that was “wrong” with them, even if they weren't sure what that was. This was best expressed by 12 year old Darrin when he sought to explain why he was taking Concerta:

Interviewer: Do you take any medication that you know of?  
 Darrin: Yeah!  
 Interviewer: Yeah? Do you know what that is?  
 Darrin: Yeah. Concerta.  
 Interviewer: Concerta. Do you know what it's for?  
 Darrin: Oh, it's to help me with me. This thing that I have. Don't know what it's called...

Interestingly, while these students said little to demonstrate a positive sense of self, in response to the question “Is there anything you would change about yourself if you could?” only seven (just under one third) said that there was:

Stop being bad. (Oliver, aged 9)  
 Just misbehavin' that much. (John, aged 13)  
 My ADHD, my learnin' ... readin' and all that. 'Coz I'm dyslexic. (Cameron, 13)

My anger. Because it's the main problem with me. (Tom, aged 12)

Clumsy. Because I get into trouble. (Darrin, aged 12)

Be polite. (James, aged 11)

Just stop being naughty. (Adam, aged 14).

One student, who was removed by DoCS from his alcohol and drug-dependent mother (whom he still sees and clearly loves) when he was just 4 years old, replied that he would like to change his *situation*:

I wish that I could go back live with my mum and everything went back, so we didn't have any trouble. Just have a fresh start. (Nathan, aged 13)

The remaining 17 students (two thirds of the 25) said no to the question of whether there was anything that they would like to change about themselves. The basis for such a refusal is complex but it indicates that even though these young people have experienced failure and rejection for most of their young lives, they understand that to change they must somehow reject who they currently are. But this would be the ultimate rejection, one that would validate all the negative things that have ever been said about them. When a person lives with constant rejection from almost every person with whom they interact, not rejecting *oneself* may be a form of self-protection that keeps these kids functioning, however imperfectly (see Graham 2009).

## Being Well

As explained in the opening quotation to this chapter, mental health is considered to influence how an individual copes with the normal stresses of life, as well as their ability to reach their potential, each of which can affect a young person's subjective wellbeing and development. Yet, the potential for medical intervention to also interfere with these developmental processes does not feature large in the discourse that surrounds mental health and wellbeing. Of great concern to me, however, as a researcher working with disruptive children and young people who have been diagnosed, medicated and excluded from school, is the individualizing effect that such responses have and how this works to reinforce the perception that both the problem and the solution lie inside the child's head, despite considerable evidence to the contrary.

Neither Zack nor Max would discuss their home lives but it was clear from the way they responded to some of my interview questions that each had experienced unspeakable pain resulting in/from family dysfunction and break-up. While Max would state upfront what he would and would not discuss (as we saw earlier in his response to the question on medication), Zack was quite open about some aspects of his life but not about others. This was ethically challenging as the majority of the interviews were conducted by research assistants who were reading from interview scripts. However, each interviewer was instructed to veer sharply off topic if any of

the participants appeared uncomfortable or declined to answer. The sudden silence of these two boys, who were both generous and patient in their three interviews with us, indicated that the experiences they have faced in their relatively short lives have left deep emotional scars. While Max was noticeably guarded from the very beginning of each interview, Zack openly volunteered information that was not directly related to the questions being asked, for example, noting that he lived with his Nan and Pop but that his older brothers were in group homes. When Zack did decline to answer at times, it was very clear that he had suffered significant trauma, indicating that his problems stemmed from something much deeper than the “normal stresses of life”:

- Interviewer: If you were making a movie of your life and it had to be real. What would be the three most important things to tell about you and your life so far?
- Zack: My Nan stopped me from going into foster care and that.
- Interviewer: (softly) Yeah . . . Can you tell me a bit more about that?
- Zack: No.
- Interviewer: Is that because you don't know? Or because . . .
- Zack: No, I know exactly what happened.
- Interviewer: No, that's all right. So just to confirm your Nan stopped you from going into foster care?
- Zack: Mmm hmm.
- Interviewer: Yeah, okay . . .
- Zack: Yeah.
- Interviewer: . . . but you don't want to talk about it.
- Zack: No.

Mental (ill)health is determined by the presence or absence of adaptive behaviours, which are types of behaviours used to adjust to and overcome life situations. A person who experiences workplace bullying, for example, might change their usual response to an antagonist by researching passive-aggressive behaviour and adopting strategies to counteract it. This would be considered adaptive behaviour. Maladaptive behaviour is a type of behaviour that is often used to reduce anxiety but the result can be counterproductive. For example, working from home to avoid the workplace bully and drinking heavily while doing so may help to reduce anxiety, but it will not alleviate the actual problem and may make it worse in the long term. Maladaptive behaviour patterns form the basis of behavioural profiles, which can be interpreted as symptomatic of disorders listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM). A fidgety, distractible child that leaves his seat to walk about the class disrupting others, for example, may be considered to exhibit behaviours that are consistent with the diagnostic criteria for Attention Deficit Hyperactivity Disorder (ADHD).

Depending on the severity of their behavioural “symptoms” children can also be diagnosed with Oppositional Defiance Disorder (ODD), Disruptive Mood Dysregulation Disorder (DMDD), and/or Conduct Disorder (CD). The prognosis worsens with each diagnosis with some researchers now considering behaviours in this family of disruptive behaviour disorders – including “verbal aggression, physical aggression, swearing, defiance towards authority figures, hyperactive behaviour,

impulsive behaviour, inattention, stealing, lack of guilt over misbehaviour, absence of empathy toward others, and violation of school rules” – predictive of future psychopathy, even referring to the children who exhibit them as “fledgling psychopaths” (Gresham et al. 2000, p. 88).

Data from classroom observations and interviews with principals confirmed that the behaviours of the students in our behaviour school group fit those described above but, while present, these behaviours did not encapsulate any 1 of the 25 in toto. Like all children, Max and Zack had no choice in the hand they were dealt, and rather than receive support in the formative early years both experienced parental, school and peer rejection and both have learned to use physical aggression to protect themselves from others. Neither believes that medication helps. This is not surprising given that medication cannot change their social circumstances. Disturbingly however, neither boy has a clear idea of what they can do to make those changes themselves, even if they do know what would make them happy in life, whether that be “just hanging out with friends” (Zack) or knowing love:

- Interviewer: Okay, right. Now, next question. What do you think will make you happy in life?
- Max: Hmm. A pony – nah, I’m kidding. Hmm. Being immortal.
- Interviewer: Why would you like to be immortal?
- Max: Actually no. Probably never going to hell.
- Interviewer: Yeah.
- Max: Or knowing what actual true love is.
- Interviewer: Hmm . . .
- Max: That’s what would probably make me happy; actually knowing when to know what true love is.

## Conclusion

The concept of “wellbeing” has become popular in many contemporary Western societies, yet it is difficult to uniformly define and measure. Rather than to refer to anything definitive, the term is commonly used as a positive frame of reference through which to promote and discuss mental ill/health. In this way, what it means to be “well” comes to be defined by the absence of psychiatric symptomatology. As discussed, there are a number of dangers that flow from this.

Firstly, normative conceptions of what it means to be *well* are at risk of imposing judgments upon young people who, while dealing with difficult issues, do not necessarily view *themselves* as unwell. Secondly, such young people may be subjected to psychological and/or medical treatments that further individualize those issues, denying broader social influences and their impacts, including the roles and responsibilities of parents, schools, communities and governments. Thirdly, young people may come to know themselves as “disordered”, which can rob them of both the voice and agency they need to overcome their circumstances. Finally, this

construction invites a preventative focus resulting in the development of treatments to prevent particular young people from “becoming” unwell, however, the potential for false-positive diagnosis and treatment presents yet another risk that must be balanced against all the others.

Whilst each of the above dangers is evident in both the clinical and critical research literature, they are typically considered individually and weighed against the risk of doing nothing. Seldom are these dangers considered collectively, even though they often operate in unison or in a sequence. When considered individually, each of these dangers pale in significance to what “might” happen to a young person from distressed social circumstances and, as a result, tend to be dismissed. In this chapter, however, each of these dangers is considered and weighed against the progress and perspectives of the individuals most affected. Ultimately, the medical model is found wanting.

The research presented in this chapter indicates that children and young people *can* and *do* internalize medical diagnoses; believing both that there is something organically wrong with them and that there is little they can do to change their situation. Interestingly, very few actually want to change *themselves*. However, by individualizing and pathologizing young people’s reactions to the conditions in which they live, dominant treatment responses can reinforce the perception that both the problem and the solution lie inside the child’s head, none of which is conducive to producing the conditions of possibility required for the development of agency and, ironically, the realization of wellbeing. For this reason, greater conceptual clarity around what it means to be “well” is urgently needed, as well as objective point-in-time analyses of young people’s own beliefs and self-characterizations by the practitioners involved in assessing youth mental health and wellbeing.

**Acknowledgements** This research was supported under the Australian Research Council’s *Discovery Projects* funding scheme (DP110103093) and a Macquarie University Concentration of Research Excellence (CoRE) grant. The views expressed herein are those of the author and are not necessarily those of the Australian Research Council. Ethics approval was obtained from the Macquarie University Ethics Committee (Final Approval No. 5201000654) and the NSW Department of Education and Communities (SERAP No. 2011027).

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Rethinking Youth Wellbeing

Critical Perspectives

Wright, K.; McLeod, J. (Eds.)

2015, XI, 222 p. 2 illus. in color., Hardcover

ISBN: 978-981-287-187-9