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The New Outsiders: ADHD and Disadvantage

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Abstract

Recent research has pointed to the uneven distribution of diagnoses of Attention Deficit Hyperactivity Disorder, with disproportionately high numbers in areas marked by poverty (Gifford Sawyer et al., 2004; Olfson et al., 2003). This chapter examines this issue of ADHD and social and economic disadvantage. Drawing on research with youth professionals from some of the most disadvantaged communities in Australia, the chapter puts forward the case that the ADHD phenomenon has highly problematic effects on the lives of children and young people in these communities. The intent is to show how the ADHD phenomenon interacts with disadvantage, and suggest how certain schooling practices that lead to the medicalization of child behavior have significant effects on people living in poverty.

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The New Outsiders: ADHD and Disadvantage

VALERIE HARWOOD

Recent research has pointed to the uneven distribution of diagnoses of Attention Deficit Hyperactivity Disorder, with disproportionately high numbers in areas marked by poverty (Gifford Sawyer et al., 2004; Olfson et al., 2003). This chapter examines this issue of ADHD and social and economic disadvantage. Drawing on research with youth professionals from some of the most disadvantaged communities in Australia, the chapter puts forward the case that the ADHD phenomenon has highly problematic effects on the lives of children and young people in these communities. The intent is to show how the ADHD phenomenon interacts with disadvantage, and suggest how certain schooling practices that lead to the medicalization of child behavior have significant effects on people living in poverty.

Inside the Magic Circle

But what lasted longer than leprosy, and persisted for years after the lazar houses had been emptied, were the values and images attached to the leper, and the importance for society of this insistent, fearsome figure, who was carefully excluded only after a magic circle had been drawn around him. (Foucault, 2006, p. 5)

Of the children most excluded from school, those that predominate are deemed to have behavioral problems. To invoke the above imagery from Foucault, these children are likely to be excluded once “a magic circle has been drawn around them. In some instances, this may involve the diagnosis of ADHD or its conceptual cousins, Oppositional Defiance and Conduct Disorder (APA, 2000). In others, an official diagnosis as such may not be assigned, and yet, because of the powerful association disorderly behavior holds with mental disorder, they are in effect, “diagnosed.” To fully understand the extent of the problem some call “ADHD”, it is important to grasp that the reach of diagnosis operates via both a formal and informal clinic (Harwood, 2006). For this reason the term *ADHD phenomenon* is a better term to use when referring to the effects of the diagnosis, since it captures more

accurately the breadth of influence of this new and worrisome cultural form, one that has reached into the very heart of education.

The ADHD phenomenon is not restricted to students diagnosed with ADHD or other behavior disorders. To assume so is, at best, naïve. It now has status as a cultural practice that is contributing new knowledge about children and young people. This has occurred to devastating effect in locations marked by intergenerational poverty (Vinson, 2007). The ADHD phenomenon is not restricted to students diagnosed with ADHD or other behavior disorders. To assume so is, at best, naïve. It now has status as a cultural practice that is contributing new knowledge about children and young people. This has occurred to devastating effect in locations marked by intergenerational poverty (Vinson, 2007). Australia, the United States, and England are each witnessing disproportionately higher numbers of children and young people from disadvantaged circumstances being diagnosed with behavior disorders (or behavior problems). In the US research by Olfson et al. (2003) noted that over the ten year period 1987-1997 there were changes from larger representation by higher income groups to significant increases in diagnostic rates in groups from “poor, near poor and low income backgrounds” (Olfson et al., 2003: 1073). More recent surveys have reported that while there is higher representation of boys, this is even higher in boys from backgrounds marked by disadvantage (Center for Disease Control and Prevention, 2005). Added to these issues is the disturbing problem of the racialization of diagnosis, with black children over-represented in diagnosis and special education classrooms (Stapp, 2009). In England, recent research has emphasized the degree to which children living in poverty have higher rates of behavior disorders, and provides the following startling estimate:

[I]f all children had the same risk of mental disorder as the highest income groups, then there would be 40.6 per cent fewer mental disorders, 59.3 per cent fewer conduct disorders (anti-social behaviours), 53.7 per cent fewer hyperkinetic disorders (ADHD) and 34.4 per cent fewer emotional disorders. (Spencer, 2008: 10)

This report maintains that similar patterns of relationship between disadvantage and diagnostic rates of behaviour problems occur in studies conducted in Sweden and Canada. The evidence is convincing: there is a grave problem with how children and young people from disadvantaged circumstances are being caught up in the medicalization of behavior.

In schools beset with issues associated with social and economic disadvantage, the behaviorally problematic child is quite often “the fearsome creature.” We

have in our schools a figure feared by pre-service teachers, for whom innumerable interventions are crafted, and who has sparked an entire sub-specialisation of teaching and psychological expertise (see Graham, Chapter 1). However, because the ADHD phenomenon draws attention to a supposed organic deficiency, it can cause us to overlook the contexts of poverty. From this perspective, drawing “a magic circle” around disadvantaged children who present with challenging behaviour at school may risk being a form of prejudice. Applying diagnoses to children and young people in poverty are actions that uncannily summon the spectre of the leper, bringing this fearsome creature forth once again into the spotlight, from whence, all so quickly, it can be removed. By stigmatising social disadvantage with psychiatric disorder, the ADHD phenomenon becomes the focus: the acceptable remedy is the supposed “quick fix” of medication, and in so doing, it becomes politically acceptable to not address the root causes of social problems.

This chapter therefore examines the ADHD phenomenon in the context of social and economic disadvantage. Drawing on research designed to secure a snapshot of the reality of ADHD and disadvantage, the chapter focuses on some of the most disadvantaged communities in Australia.¹ In these locations I interviewed child and youth professionals who told of the rapid rise of behavioral diagnosis in these communities, the spread of medication and the contemporary cultural custom of “being ADHD.” In the discussion that follows, I investigate the ADHD phenomenon and its association with disadvantage as it occurs in Australia. To do so, I outline an approach for conceptualizing disadvantage to examine the ADHD phenomenon within the context of two fundamental elements for wellbeing, firstly, “affiliation and belonging” and secondly, “control over one’s environment”. Throughout the chapter I aim to raise the discomfiting question: What are we doing as a society, when in locations marked by disadvantage, children and young people are forced to become fearsome creatures and live out psycho-medicalized childhoods?

The ADHD Phenomenon

While there is much debate over the validity of the ADHD diagnostic category, there is little dispute regarding the spiralling numbers of diagnoses of ADHD and related behavior disorders. As signalled in other chapters in this collection, at issue is the privileging of one account of behavior and the stranglehold this has over understandings of contemporary childhood and youth. The ADHD phenomenon widely influences how young people’s behavior is understood and interpreted. Children and young people

frequently cite ADHD/behavior disorders as the cause of their problems, and they do this irrespective of diagnosis. Underlying much of these assumptions is the belief that the problems are irreversible.

Irreparable childhood behavior problems, problems enunciated by authoritative diagnostic prowess, problems that have reach beyond the clinic: this is precisely what is at issue with ADHD. The alarming rates of diagnosis, combined with the predominance of diagnosis in socio-economically disadvantaged settings are cause for alarm. The ADHD phenomenon is the subject of national and international attention, and there are warnings that it could become “the leading childhood disorder treated with medications across the globe” (Scheffler et al., 2007). Between 1993 and 2003, ADHD medication usage had increased worldwide by 274% (Scheffler et al., 2007), with Australia ranked third highest for psycho-stimulant consumption (Mitchell, 2004). The United States and Canada are ranked first and second respectively. Australian rates of consumption of the ADHD medications, dexamphetamine and methylphenidate have risen steadily by 31% and 30% respectively each year between 1984 and 2000 (Berbatis et al., 2002), and the numbers of children and young people in Australia with ADHD are estimated to be at 11.2% (Sawyer et al., 2002).

In Australia, rates of medication are highest amongst young people in disadvantaged communities, where school outcomes are low and there are high levels of youth unemployment. There are also questions being raised over the levels of young children “in state and foster care” who are on ADHD related medication (Graham, 2008, p. 89). Australian studies have reported demographic patterns that point toward a connection between disadvantage and high rates of ADHD diagnosis and medication (Sawyer et al., 2002). There are significantly higher prescription rates of ADHD medication for children where there is low-income and parental/caregiver unemployment (Sawyer et al., 2002) and in low socio-economic areas (Social Development Committee, 2002). A South Australian study (Reid et al., 2002) found the highest prescription rates of ADHD medication occurred in areas of low socio-economic status and high unemployment in Adelaide’s northern and southern suburbs. The reported high numbers of socio-economically disadvantaged children and youth prescribed ADHD medications has been flagged as a concern for pediatricians, who are at risk of “medicating for social disadvantage” (Isaacs, 2006, p. 44).

There is contention over the claim that disadvantaged communities in Australia are more likely to have large numbers of school-aged young people with ADHD and behavior disorders and have elevated rates of prescriptions

for ADHD medications. A study by Buckmaster (2004) points to the inconsistency across federal electorates in relation to socio-economic factors. However, there is good cause for mounting the argument that in locations of disadvantage, for many children (especially boys) there is the risk of being diagnosed with ADHD. Research by Reid, Hakendorf and Prosser (2002) on data collected in South Australia between 1990 and 2000 from ages 0 to 18 found distinct demographic patterns in medication rates and identified clear patterns that pertain to ADHD and disadvantage.² More recently, Prosser and Reid (2009) have published further research on patterns of psychostimulant medication and ADHD in South Australia for the period 2000 to 2006, reporting geographic variation and the issue of socio-economic status. Noting the difference in the Adelaide metropolitan area, they report,

...there was a 20-fold difference between the highest and lowest SMR [standardized medication rates] in the present study, with the correlation between SES and SMR significant for both periods. The highest SMRs tended to be in areas that are predominantly lower SES with high unemployment. (Prosser & Reid, 2009, p. 345)

My research into patterns of ADHD medication in Australia echoes these reports, with communities with high rates of medication for ADHD also being places of considerable social and economic disadvantage. For this investigation I examined four Australian states: Victoria, New South Wales, South Australia and Western Australia. Using data from *'Medication for Attention Deficit/Hyperactivity Disorder (ADHD): An analysis by Federal Electorate'* (Mackey & Kopras, 2001), together with the *Socio-Economic Index for Areas (SEIFA)* (Australian Bureau of Statistics, 2001) a distinctive pattern emerged. Areas in each state that had high prescription rates also had low scores on the SEIFA index (low representing the most disadvantaged). For each of the four Australian states, I selected the locations with high prescription rates and low SEIFA scores, and then located and interviewed community/youth service professionals for each area. This resulted in four in-depth interviews in each location, with professionals from disciplines that included psychology, community youth work, youth recreation and social work. In three of the states these locations were in outer metropolitan areas (New South Wales: Western Sydney; South Australia: Northern Suburbs of Adelaide, Western Australia: Southeast corridor of Perth). In Victoria, the highest rates were in two regional areas, outer Geelong and Gippsland, with the interviews conducted in Gippsland, eastern Victoria.

The findings from these interviews reveal that young people living in disadvantaged communities with high rates of ADHD/behavior problems are

exposed to narratives of diminished futures, futures with low expectations for employment, lack of educational success, adult mental health problems and the risk of future involvement in crime. These professionals described how perceptions of child behavior, from among the children and young people and extending to those around them, were influenced by the ADHD phenomenon. This suggests that serious questions need to be asked about the consequences of ongoing exposure to the ADHD phenomenon in these communities. In the remainder of this chapter my aim is to outline the key issues of disadvantage and ADHD, as were highlighted by the professionals, who together had extensive experience working in much maligned communities where the children and youth were all too often typecast as “fearsome figures.”

Conceptualising Disadvantage

When considering the very real complexities of people’s lives, an understanding of disadvantage is required that can capture its multidimensionality and the ways in which facets of disadvantage interact. Research that focuses only on social class can be found wanting because of the somewhat limited attention given to the conceptualization of disadvantage. Recent research by Wolff and De-Shalit (2007) goes some way to providing a nuanced understanding of disadvantage, one that prompts comprehensive interrogation of disadvantage and its discontents. Their work is drawn from empirical studies in England and Israel where a total of ninety-eight interviews were held with people “on both sides of the welfare services, i.e. social workers, educators, people who work with asylum seekers, doctors, nurses on the one hand, and elderly people, refugees, homeless people, health patients and so on, on the other” (2007, p. 195). The argument put forward is premised on the idea of the “pluralism of disadvantage”, which takes the perspective that disadvantage is caused by several factors. The opposing view would be what is described as a monist approach, where if disadvantage were not plural, then one remedy would alleviate the cause of least advantage. As they write,

[W]hen we argue that disadvantage is plural in nature we mean only that there are some cases where a shortfall in one dimension cannot be adequately remedied by greater provision of another good, even when this good is recognized as valuable by the compensated party. (Wolff & De-Shalit, 2007, p. 34)

Building on this pluralist conception of disadvantage, Wolff and De-Shalit (2007, p. 182) propose defining disadvantage in terms of “a lack of genuine opportunities for secure functionings.” This view takes the position that the

achievement of certain “functionings” is necessary for wellbeing; and consequently, the inability to achieve these leads to disadvantage. In their work Wolff and De-Shalit (2007) draw on the Capability Approach of Amartya Sen (1980) which has been developed by Martha Nussbaum (2006). The Capability Approach advocates that the focus be placed on what can be achieved by a person (their capabilities) in order to live well. Nussbaum (2006) has proposed a list of ten Central Human Capabilities. Wolff and De-Shalit’s (2007) research in Israel and the UK has modified this work to six functionings, a term that they use to denote what we need in order to “live well.” These are: life; bodily health; bodily integrity; affiliation or belonging; control over one’s environment; and sense, imagination and thought (Wolff & De-Shalit, 2007). The plural approach to disadvantage is of significance in education, since it provides for a means to investigate each of the six categories of functioning (not just, for example, economic resources alone).³

Disadvantage, then, can be grasped as the inability to achieve secure functionings. Of particular importance however are the ways that some functionings may support or impede others. Wolff and De-Shalit (2007) term these “fertile functionings” and “corrosive disadvantages.” In terms of the latter, a corrosive disadvantage is “where a disadvantage in one functioning leads to disadvantages in others” (Wolff and De-Shalit, 2007, p. 133). The influence of corrosive disadvantages leads to the suggestion that the least advantaged can be identified through investigating “clusters of disadvantage.” This “clustering” occurs when several secure functionings are not being achieved. A key example cited by these authors is Sen’s (2000) argument concerning how social exclusion is connected to poverty. This has substantial repercussions when we take into account the ways in which *both* the ADHD phenomenon *and* poverty contribute to social exclusion. A point to which I later return in this chapter.

Fertile functioning can be identified when “doing well in one functioning... will lead to improvements in other functionings” (Wolff & De-Shalit, 2007, pp. 133-34). Wolff and De-Shalit (2007) identified “affiliation and belonging” and “control over one’s environment” as the two functionings that are of special importance, with affiliation and belonging perceived as the most fertile. Research has identified the importance of autonomy and participation for good health (Marmot, 2004), and also how social exclusion can be detrimental to other capabilities (Sen, 2000). Nussbaum (2006) also emphasizes these, and underscores the importance of participation in institutions that support affiliations. Arguably, education is one of the most important institutions of affiliation in our society. What then, may be

occurring in locations where there are both high diagnostic rates of ADHD and related disorders *and* social and economic disadvantage? Given the special importance these researchers have attached to affiliation and belonging and control over one's environment, how might an account of these inform understanding of the ADHD phenomenon and disadvantage? It is to this consideration that I now turn.

Affiliation and Belonging

One of the uncomfortable realities that the youth professionals reported was the degree to which the young people were not connected with the institutions of affiliation, institutions such as schools, youth centers, sporting clubs, and places of meaningful employment (and for many, with the high rates of youth unemployment, there was no employment). Low rates of attendance, truancy, early school leaving and behavior problems are marked issues of concern. Robert, the youth professional from the site in outer metropolitan Adelaide, South Australia, worked in a community health service. He described his experience at the local secondary school, where he had been invited to assist as a school counselor. "When I was there in the fourth term... attendance was I think below fifty-four per cent for the whole school." The service where Robert worked provides counseling and support to young people, as he explained, "we deal with homelessness, we deal with a lot of mental health issues that are outside of the periphery of major health institutions. We deal with masses of behavioral type issues." To qualify "masses", Robert stated, "I'd venture to say off the top of my head that I reckon it would have to be close to about seventy per cent of the clients that you see have one or more types of [behavior disorders]." The numbers of young people coming to the service with these types of issues had been steadily increasing, and in the last two years, so had the numbers of young women with behavior related issues.

Whereas four years ago I may have had a referral, you know, a young fourteen year old boy and there may have been behavioral issues at school, and some minor family dysfunction - or something like that. Now when I get a referral, you know it's a fourteen year old that's got behavioral issues at school, there's major family dysfunction, they've got an ADHD or ADD or some other formal diagnosis, they've got drug and alcohol issues, there's sexual abuse issues, there's homelessness pending. Nothing is simple anymore.

David, the youth professional from the outer metropolitan Perth site worked on a team that provided recreation and outdoor activities for "at risk" young people. He described how schools would attempt to refer young people who

were regular absentees, “I’ve found that those kids who are truants, they’re non-attenders, they won’t participate. They might come for one or two times and that’ll be too much for them – and you just – they’ll fail – they’re better off doing something else.” The schools in the areas serviced by David’s youth recreation program sought to place their students away from the school. While previously this recreation program was free to schools, now there is a charge.

They pay for us. Before, a few years ago, we did all this and charged them nothing. But they get money now to do these alternative education programs. You know, some schools now seem to benefit from outsourcing and getting those kids off campus.

While there are likely to be cogent arguments on the part of the school for engaging these out of school programs, the fact remains that the students are moved away from the school. These observations from this youth professional are salutary insofar as they prompt a reconsideration of the possible complications created by “getting kids off campus”, one of which is the contribution it could make to breakdown in institutional affiliation (see also Slee, Chapter 3).

Cate, the youth worker in regional Victoria, reported on the high numbers of young people who are unemployed in the area, who have left school early, and for whom there were limited or no connections beyond the institution of the school. Cate estimated that around fifty per cent of young people were unemployed, although she did suggest that this be checked. While not at fifty per cent, the rate is extremely high, with the region figuring in the ten top places in Australia that have the highest youth unemployment. Based on figures from 1996, the youth unemployment rate in Gippsland is 21.3% (Muir et al., 2003), and in 2006 the rate for the region was reported as 32.2 % (Burke, 2006).⁴ The picture of youth in this area is one where large numbers of young people are not connected to sites of affiliation.

Disconnection from schools can be brought about by the ADHD phenomenon, a point made evident in the interviews in New South Wales and South Australia. It is important to emphasize that this issue of disconnection is not a problem limited to Australia. In a group interview conducted in the San Francisco Bay Area, United States, three youth professionals described the extent to which the ADHD phenomenon is marked by social and economic disadvantage, and by racism. These youth professionals explained how, rather than increase participation, diagnosis can in fact lead to disconnection from school. They cited examples of young children who were forced from school, required to undergo medication, and

of parents who, because of their wariness of racism by what they viewed as an essentially 'white' system, elected not to pursue special education provisions. The New South Wales site in Western Sydney, two youth professionals, Danielle and Sharon, were interviewed together. Referring to the local secondary school, Danielle explained,

Well, we've got kids here that are misbehaving at school and they ring to make an appointment here and then I'll get a phone call from mum to say 'The school has said to us, first we have to go to the pediatrician to get them medicated, then we'll come to you'.

The fabric of childhood and youth in this community is permeated by the ADHD phenomenon. The requirement to diagnose and medicate that is imposed onto the children situates their relationship to the school as one in jeopardy, and significantly, as one that is to a sizeable extent beyond the control of the child and their family. This raises the issue of being treated with dignity. This right is at issue in this school (and in many others, see Graham, 2008) where one is forced to take medication as a condition of acceptance in schooling. A further point to make here is that these threats can be literal or perceived. We would be failing in our comprehension of the impacts of disadvantage if we do not take into account the imbalance of power between schools (and education systems) and parents and children in such disadvantaged communities.

Disconnection from institutions extends to social relationships and knowledge. An invaluable insight into the process of loss of affiliation was described by the New South Wales youth professionals when they discussed the ADHD phenomenon and parenting. Danielle described one of the home visits to an eighteen year old mother and her baby. The young woman lived with her sister, who had a two year old child, both of whom were present at the home visit. Prior to going, the eighteen year old told her, "Oh you know, my sister's got this kid who's ADHD." Danielle then explains,

So when I did the home visit I'm expecting to see this, you know, really wildly out of control kid. I wasn't actually visiting that part of the family I was just visiting her and her issues. I was there I think for an hour-and-a-half just talking with her. The [sister's] little boy sat and was watching TV the whole time. Her baby was placed in front—you know on one of those baby things just watching it. And then at the end you know he—he got up and he was wanting to do something like go and play. And the mother and the sister both go, "See! See how much energy he's got". "You know, he's definitely ADHD." And you're thinking, "Mm. That's interesting". It was — would you expect a two year old to sit for so long — no toys in the — nothing— in the house apart from that TV?

After this observation, Danielle asked the other young mum about the two year old and to her surprise, she described with much pride how she had trained the child to sit in front of the TV. Danielle asked, "Oh, how is it that he's been able to sit down there?" To which the young woman replied, "Ever since he was little, [I've done this] since he was a baby. Now, he wouldn't watch TV at first but I would place him there and it would get longer and longer." Here Danielle emphasised that the young woman was *proud* of how she had taught the child to sit in front of the TV. Reflecting on this comment, she explained that, "When I was a mum I never even thought of putting kids in front of the TV." But what had occurred for this young woman is that it was seen to be the thing to do. As Danielle pointed out,

If you think that when you're a child and what you do is watch TV and that is what you do. She was actually teaching the child a skill. But then [she was] wondering what to do with all that energy - which you would have afterwards, and then labelling it as ADHD.

As Danielle made clear, the young woman had not had her young child diagnosed: she had given him the label herself. Her child was to her mind a child with ADHD, and one likely to be officially diagnosed at some point in the near future. Both Danielle and Sharon discussed how the two young women had a perspective on training their children, one that they had learned. UK research has reported that having a child labeled with ADHD effectively "disorders" the mother (Bennett, 2004). The mothers researched in Bennett's (2004) study were aged between 30 and 45 years, and were influenced by discourses of ADHD that positioned them and their mothering as problematic, however, this aspect of the ADHD phenomenon is international in its reach (see emerald & Carpenter, Chapter 6). The interpretation put forward by Danielle and Sharon breathes a startlingly divergent understanding of these young women. Both women noted how their critical views on ADHD differed from professionals from other services, including the teachers who would expect and anticipate diagnosis. Rather than situating these young women as pathologized, the two youth professionals understood their disadvantage in terms of their lack of affiliation with wider parenting, school and community networks. Importantly, this was grasped in concert with the insight on the workings of the ADHD phenomenon – an invaluable perspective that the two youth professionals had developed and honed in their work.

Disconnection from regular institutions such as schooling, regular

employment, and broad social networks impacts on affiliation and belonging. What is marked, and I argue represents an intensification of disadvantage in these communities, is the influence of the ADHD phenomenon. In short, there is a stark differentiation in the patterns of affiliation and belonging of middle class parents and those of the parents in these communities. Added to this are the challenges faced by young parents in these communities. It is clear from the observations shared by these experienced youth workers that these young women are striving to do the best for their children: they sought to train and educate their infants - and yet all too frequently assumptions are made about "lack of care." For example, they showed much pride in the ability of their children to sit still in front of the TV, and had warmly welcomed the youth professional into their home. The young mothers were striving to care for the children, but they had limited affiliations to institutions and networks that provide knowledge of parenting approaches. As such they had a limited repertoire of approaches, and drew heavily on what was the dominant approach in their immediate network - and one that was heavily infused with the beliefs associated with the ADHD phenomenon.

Taking this sort of observation into account can be extremely beneficial for redressing assumptions about behavior and poverty. An appreciation of the subtle workings of the ADHD phenomenon and disadvantage may well help to turn around professional and societal misunderstandings about these young parents: the keenness to educate is an untapped resource. The young women had a restricted range of resources for developing their parenting. Paradoxically, it was precisely via the presence of the ADHD phenomenon that the young women were, unknowingly, contributing to the social construction of their own child as "behaviourally disordered." This is a point that could all too easily be overlooked, and one that attests to the import of conceiving the ADHD phenomenon as a cultural practice. There is also what could be termed a "coercive relationship" with specific institutions marked with humiliation and, as Goffman (1963) terms it, stigma. In these communities with high levels of ADHD and high levels of socio-economic disadvantage, it is ordinary to be a patron of mental health services, of social services and have links to the criminal justice system. What we must remind ourselves is that, while it may be ordinary, it is not without stigmatization. As such, we find yet another aspect of disadvantage in communities affected by the ADHD phenomenon, one that is a very real threat to people's right to dignity.

Control over One's Environment

Soft skills are of the essence for negotiating the medical interventions that the parents in these communities are all too often compelled to pursue. Being able to discuss, understand, disagree and seek other opinions are significant rights for health. However, the experience of the people in these communities shows how this is vexed by disadvantage. Robert described the alarming situation in the South Australian site where one pediatrician had astonishing influence over the medication of children in the community. Firstly Robert explained the extent of the patterns of medication in the community.

Well we have, um—we have a *very* famous pediatrician down here. Dr. T was the king of ADHD diagnoses and used to put individuals on absolutely massive doses of dexamphetamine and Ritalin. When I mean massive doses, I'm talking big doses, I mean we would see some individuals here that had had contact with Dr. T. and would be on thirteen to fourteen doses of dexamphetamine per day. Even some individuals past twenty tablets a day. And then [there were] all the medications, of course that are prescribed [to] fix up the side-effects of using amphetamine, you know, like and those types of medications they have to aid sleep and some occasionally antipsychotic medications.⁵

The very nature of disadvantage in these areas renders the development and deployment of soft skills difficult, if not impossible. How do parents (and children) in these communities disagree and negotiate with the school, when for example, they are told that their child cannot return unless accompanied by medication? The power imbalance between the school on the one hand, and the parents and their children on the other, is striking. Soft skills “allow people to ‘work the system’: to get their children into better schools; to get medical attention when they need it; to get cheap short-term loans in emergencies; to manage their savings and investments” (Wolff & De-Shallit, 2007, p. 144). The question is, do the people experiencing disadvantage have access to the much-needed soft skills to “work the system”, skills that are necessary such that they can have a degree of control over their environment? The interviews (both in Australia and those held in the United States) indicate otherwise: that the potential for exerting control is limited. And yet, soft skills are vital in education, and most pressingly, are vital in disadvantaged communities.⁶ Take for example the soft skills needed to negotiate with the school’s expectations for child behavior, and the associated demands for how this behavior is managed. What became evident throughout the interviews was that parents developed knowledge of medication, but that this knowledge, and the associated soft skills, was restricted to patterns that kept them *within* the ADHD phenomenon.

For example, parents in the South Australian site knew ‘how to manage

the system' in relation to benefits associated with an ADHD diagnosis. Robert, the youth professional in South Australia acknowledged that while "the community is not terribly well educated about ADHD and all of the discourse around it," they do have key knowledge that informs their approach to ADHD. As Robert emphasised, "*they are knowledgeable about what it means*. They're knowledgeable about what it means in terms maybe of management for their child. And, you know, whether they will get assistance and those types of things". Similar to the New South Wales site, community knowledge existed on how to secure assistance and medication. This could be interpreted as demonstration of soft skills. Contrary to this interpretation (which arguably is all too easy to fall back on) it is crucial to appreciate the degree to which knowledge and bargaining power are restricted. These parents are not in a position to bargain with the schools, with the public education system, and least of all with education markets.

Autonomy in the workplace and worker control: Just as Wolff and De-Shalit pay attention to the workplace as an integral site for control over one's environment, so too can education be considered in terms of autonomy and control. There are concerns for the children and young people within schools and in their access to education, and also for the parents and their capacity to exert influence. Here the difference between parents with varying socio-economic circumstances is profound. The extent to which people in these communities lack the ability to control and influence education is cause for concern. An exemplar being the extent to which the parents and the children were not able to control their access to education. In relation to medication, Danielle the youth professional from the New South Wales site stated, "Well the parents, and I don't know if this is a generalization in this area, if the teachers says, 'this is what's going on' then the parents sometimes do it. Like there's a lot of power from the school for that to happen". In agreement with this observation, Sharon added that while, "Danielle and myself might disagree with the teacher (or even the principal), I don't think many people around here would." The point here is not that the parents choose to agree, it is, rather, that in their view the principal and teachers exert an overpowering influence. A counter perspective could be that the parents are able to exert influence and control in education via health and specialist services. For instance, in the South Australian site, the parents had expectations for forms of treatment, and quite frequently, demanded a specific outcome from doctors.

[Dr T.] was very well known. I mean, you know, the other thing that happens when

this pathological discourse becomes widely accepted in the community, parents with difficult children start to become diagnosis experts themselves. So they would go to someone like this Doctor and they would say, “My child has ADHD- you know, he needs medication, what are you going to do about it?” And so they would get the response that they wanted. You know “Oh yes, well of course, we’ll medicate them”. And that would be the way it is. So, they get the response that they want.

Robert shared his insight on the community to explain how, via the influence of Dr. T. and the influence of pathological discourse, medication became *the* normal remedy for behavior problems. In the New South Wales site, the two youth professionals described an example where the local secondary school, “would not teach the child” until that child had been medicated. More ominously, when parents said no to medication (that is, using this frame of interpretation they exerted their right of autonomy to control education) they met with great difficulty, not least because of the medical implications of ceasing medication. Robert explained that “some parents in the community say things like “I don’t like, I didn’t like what the drugs were doing to my son or to my daughter”, “I just didn’t feel like it was the right thing to be giving them that medication—so I stopped it.” When they did cease medication, often without medical consultation, they would be faced with the problems associated with sudden withdrawal (see emerald & Carpenter, Chapter 6). Robert described how such withdrawal had ramifications on the child and family. In many cases the cessation of medication was not accompanied with appropriate information or behavioral strategies, and would lead to exasperation by the parents, which frequently resulted in the return to medicating. Again, the situation was exacerbated by disadvantage, with limited access to resources, and already pressingly difficult life circumstances.

Poverty as a corrosive disadvantage: Poverty is a key circumstance for which we must account if the implications of the ADHD phenomenon and disadvantage are to be adequately comprehended. There are numerous examples that can illustrate the direct impacts of poverty. Below is one example that demonstrates how poverty impacts control over a child’s health.

So the fact of the matter is that in the state of South Australia access to a psychiatrist is so poor— for public patients—that you know, the majority of ADHD diagnoses come—and ODD, and all of those type of diagnoses, come from pediatricians.

In the above quotation Robert is describing who tends to medicate. Recalling the discussion of the pediatrician who had the nearest clinic to the community, the consequence of poverty on health and education are

unmistakable. The parents, indeed the entire community, were drastically influenced by the diagnostic and prescribing practices of this *one* pediatrician. This is a case where the circumstances of poverty have placed people at significant risk of hazardous levels of medication. In the South Australian site, a significant number of children from one community were plunged into the devastating reality of the worst features of ADHD phenomenon: intense medication regimes that harm young bodies and minds.

Illicit selling of psychostimulant medication is a common occurrence in the South Australian site. Robert talked about the “young individuals and families that sell it here.” In Western Australia, David suggested that parents are possibly engaging in the selling of medication, they “would be pinching their kid’s medication and selling it at the local footy club or, you know, that sort of stuff.” While David made it clear that he was speculating to some extent (regarding where they might be selling the psychostimulants), the selling of medication has been noted as an issue of concern (Harwood, 2006). To emphasise the wider cultural accounts, scenarios of parents taking their children’s ADHD medication have been dramatised on television programmes such as *Desperate Housewives* (Cherry, 2004). The practice of parents and family members taking children’s medication – and the selling of it – was clearly a familiar practice noted by youth professionals in two of the sites (the topic was not raised in either of the interviews in NSW or Victoria); one that reveals the desirability of their physiological effects. What was stressed by Robert was the consequence of selling off their children’s medication. Robert made this clear in the following statement,

It’s pretty common [selling the medication]. It’s been getting harder in recent years I think because, you know, if they’re using the Dexi themselves and then selling it, I think they run out of their prescription prior to the twenty days, which is by law before the pharmacist can refill the script.

The consequence is that the children then run out of their allotted medication. Clearly, for these children, poverty together with the ADHD phenomenon has the effect of compounding the experience of disadvantage.

Probing into the selling of medication (beyond an argument of urgent need, for example), an instructive point can be drawn from Wolff and De-Shalit’s discussion of poverty and the experience of progress. The two authors cite the response from one of the participants in their study, who had outlined the relationship between saving and expectations for the future.

People invest for the long run and save for the future, he claimed, when they have

had a positive experience of progress. In other words, people whose lives can be described as a *process of progress*, interpret time in a positive and optimistic way... However, the very poor have not experienced life this way. For them there was no progress, and therefore there is no sign that the future should be better than the present. (Wolff & De-Shalit, 2007, p. 149)

The outcome being that for the very poor, because of this lack of faith in the future, money gets spent on immediate gratification. This, as Wolff and De-Shalit (2007) suggest, goes some way to explain to an outsider why and how those in desperate poverty spend money. Such views present an interpretation of parental spending practices that takes the complexity of the effects of disadvantage into account. Without such a perspective it could be easy to cast dismissive judgment of these parents, judgment with limited vision of the insidious workings of disadvantage. Beyond an explanation that cites direct material need (such as food) the above perspective may contribute to understanding why parents may sell medication for short-term gratification. Taking Wolff and De-Shalit's (2007) proposition that poverty is a corrosive disadvantage, it is undoubtable that poverty is a corrosive disadvantage for education in these communities affected by the ADHD phenomenon. Adopting a pluralist approach to disadvantage therefore requires an outlook that takes account of poverty together with the other functionings, most importantly, affiliation and belonging and control over one's environment.

Closing the Magic Circle

Routine prejudicial practices situate disproportionate numbers of the young in disadvantaged communities as having a serious mental disorder. The ADHD phenomenon casts a pall over childhood in these disadvantaged communities, becoming a narrative of childhood that invokes the fearsome creature. In these contexts the ongoing rationalisation of the psychopathologisation of young people is only possible when accompanied by the dismissal of social, cultural and systemic problems. It is when these are ignored that the fears of the fearsome creature gain the most ground.

Comprehending the ADHD phenomenon together with an understanding of disadvantage goes some way towards grasping the predicament of the children and parents in these communities. Such a view can take educators beyond the simplistic interpretations that are afforded by the culture of behavioral diagnosis. The importance of such understanding to educators cannot be underestimated. This is because teachers have such a central role in the lives of these children and young people.

To close, I turn to a story told to me by the two youth professional from the NSW site. Their story demonstrates value of developing fresh understandings of children and young people living in disadvantaged circumstances. The told of their experience of learning about and appreciating a distinctive community practice: *sharing bicycles*. Describing this story, Danielle recounted one of the children's explanations, "[they would say] 'I don't have a bike, but my next door neighbour has a bike, so I use his and we just share stuff. We just share whatever we've got.'" Observing this behavior, she decided to bring a bike from home to the Youth Centre. She explained that "having witnessed these communal bikes and [we] thought 'well, let's experiment'." Sharon then continued the account:

Every week I see it [the bike] with a different kid. And last week I asked the original kid where it was. And he goes, 'I don't know', [then] he goes, 'I think Jarrah has it, I'm not sure. It's around.'

Both of the youth professionals stressed how they *actively sought to challenge their own assumptions*. In so doing, they had learned to see the community from a perspective that questioned dominant views of pathology. As Sharon explained, it was important to develop such views, because, "it's something that's quite good. And often everything's just painted bad. But things are shared and people do look after each other." The fundamental point to absorb from this story is that it was because the two youth professionals learnt to look at the children, youth and community around them in a different light, that they were able to move beyond beliefs narrated by the diagnostic lens and assumptions about poverty and disadvantage. This enabled them to see a valued practice and to generate understandings that go some way to disrupt prejudice about disadvantage. Learning to see the good, then, is not to say, well, they may be poor, but they are happy. Rather, it is to turn the gaze back upon ourselves and our beliefs about people marked by the dual discrimination of diagnosis and disadvantage.

Grasping the workings of the ADHD phenomenon together with the ways in which it impacts upon disadvantage can assist in identifying and challenging our assumptions. This is a practice that yields hope for changing these assumptions, but only if we are prepared to open our eyes.

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California and England between 2007 and 2008. Identifying information has been removed, including people's names, locations, schools and descriptions that could reveal identity.

² They state, "In our data the highest SMRs (Standardized medication ration for the postcode) tended to be located in the northern and southern suburbs. These areas are predominantly of lower SES, with high unemployment. SES has previously been suggested as a risk factor for ADHD" (Reid et al., 2002, p. 7).

³ The Capability Approach has been used in educational research to investigate which capabilities are important for addressing issues such as gender equality and education (Walker, 2007), and children's needs for engagement in education in developing countries (Biggeri, 2007). A discussion of the Capability Approach and inclusive education is provided in Graham and Harwood (in press).

⁴ The region has high numbers of people in receipt of health care cards, and high numbers of single parents (Latrobe Valley Ministerial Taskforce, 2001; Vinson, 2007).

⁵ This Doctor was eventually investigated, and Robert stated that he was not certain if the Doctor had ceased practicing.

⁶ "Soft skills, as employers describe them, are such things as communication and people skills, teamwork skills, demeanor, motivation, flexibility, initiative, work attitudes, and effort" (Moss & Tilly, 1996, p. 253).