Neurobiology in public and private discourse: the case of adults with ADHD

Bröer, C.; Heerings, M.

Published in: Sociology of Health and Illness

DOI: 10.1111/j.1467-9566.2012.01477.x

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)

Download date: 26 Feb 2020
Neurobiology in public and private discourse: the case of adults with ADHD

Christian Bröer and Marjolijn Heerings

Department of Sociology and Cultural Anthropology, University of Amsterdam, The Netherlands

Abstract

How do people describe their health? How do their descriptions relate to public definitions? This article focuses on adult attention deficit hyperactivity disorder (ADHD). We look at Dutch adults who adopt the ADHD label and ask: which discourses structure their descriptions of ADHD? How do these relate to the dominant public discourse on ADHD? Do people use, for example, neurobiological explanations of ADHD? The research makes use of Q-methodology, which combines a discursive relational approach with factor analysis. We examine five different personal discourses that partly differ from the public discourse. People borrow neurobiological, psychological, sociological and even holistic arguments from public discourse to come up with a distinct set of discourses. Neurobiology resonates among adults with ADHD but does not dominate their thinking. Contrary to our expectation, this supports reflexivity instead of discipline theory.

Keywords: public and personal discourse, Q-method, brain, hyperactivity

How do people describe their own health? How do their descriptions relate to publicly available definitions? This question has been central to our investigations on health risks, protests and noise annoyance in several European countries (Bröer 2006, 2007, 2008, De Graaff and Bröer 2012, Kroesen and Bröer 2009). We found that specific policy discourses structure people’s perception. In this contribution, the broader public discourse’s relation to everyday utterances is central. We focus on Dutch adults who adopt a particular diagnostic label: attention deficit hyperactivity disorder (ADHD). We analyse how adults define ADHD and how this is related to the publicly available definitions. Can one discern, for example, somatic, psychic and social explanations of ADHD? We are particularly interested in whether neurobiological explanations of ADHD structure people’s descriptions. To bring this to the fore, we employ a promising yet underused methodology: the Q-method.

Professional and lay understandings

How should we understand the social shaping of illness experience? Social scientists point to dominating practices under the headings of discipline, surveillance and control. Parsons, for example, has stressed how we are coerced into a sick-role (Shilling 2002) while Freidson
(1986) has pointed to the power of professionals in medicalisation. De Swaan (1990) speaks about ‘proto-professionalisation’: the process of ‘professional knowledge’ replacing ‘lay views’. The experience of health and illness, then, is shaped by medical practice. Developments in medicine are therefore crucial for analysis. In recent decades medical and especially mental health practice has stressed the somatic causes of illness. The prominence of genetics in the 1990s was followed by a focus on brain functioning (Mayes and Horwitz 2005) – developments which have been interpreted as biomedicalisation (Clarke et al. 2003).

We briefly examine two assumptions contained in these arguments: first, the assumption that one specific form of knowledge – recently neurobiology – dominates the field of medicine (domination assumption); second, the assumption that people make this knowledge their own (colonisation assumption).

Dominant discourse
A number of authors call into question the existence of a single, uniform somatic explanatory model in (clinical) practice. Hedgecoe (2001), for example, shows that genetic explanations have been prioritised for schizophrenia, but do not rule out non-genetic ones; what he calls enlightened geneticisation. Weiner and Martin (2008) extend this argument for coronary heart disease and show how genetic models are contested in clinical practice and among patients. In his research on neuroscience and personality disorder Pickersgill (2009, 2010, 2011) finds that clinicians themselves are flexible in dealing with neuroscience and include social and psychological factors in their reasoning and therapy. Shostak (2003) makes a similar point for genetics.

Nevertheless, soma, psyche and society do not carry equal weight. Hedgecoe speaks of prioritising genetic arguments. Rose (2003: 57) argues that while non-somatic arguments are not excluded from the diagnosis and treatment of mental illnesses, they ‘must “pass through” the brain and its neurochemistry’. Pickersgill (2011: 449, see also 2009) even speaks of a ‘technosomatic imperative’.

We therefore need concepts that describe the relationship between different kinds of knowledge. Building on Hajer’s discourse theory, we call a certain kind of knowledge dominant when it assumes centrality: all utterances refer to it, while other kinds of knowledge are only referred to occasionally (Hajer 1995). Dominance is furthered when a certain form of knowledge is institutionalised through law, practice, policy or organisation. Rose and Hedgecoe’s descriptions of genetics and neurobiology are dominant in the sense that these forms of knowledge are central to their fields of study, though they do not rule out social or psychological explanations. Dominance, furthermore, needs to be spelt out for different fields. In clinical practice, a nuanced approach can prevail while in public one approach might override the others.

Colonising subjectivity
We now turn to the second assumption: that a dominant form of knowledge is imposed on people. Rose (2007: 188) argues:

... we human beings have become somatic individuals, people who increasingly come to understand ourselves, speak about ourselves, and act about ourselves – and others – as being shaped by our biology.

Rose thus discerns a shift from a psychological to a biological conception of self in the knowledge practices of professional medicine:
While our desires, moods, and discontents might previously have been mapped onto a psychological space, they are now mapped upon the body itself, or one particular organ of the body – the brain. And this brain itself is understood in a particular register. In significant ways, I suggest, we have become ‘neurochemical selves’ (Rose 2007: 188).

In his article ‘The shifting engines of medicalization’ Conrad (2005) details how professionals, biotechnology, consumer demands and managed care further strengthen medicalisation. Consumer demands in particular are so strong that people at times seem ‘eager for medicalisation’ (Becker and Nachtigall 1992: 456). When authorities refuse to recognise a health condition, this constitutes what Dumit (2006: 577) calls ‘illnesses you have to fight to get’ or ‘contested illnesses’.

These observations suggest that professional knowledge is not taken up in as straightforward a manner as Parsons’ sick-role concept implies. People even strive for a disease label that is not socially sanctioned. We further mention Parsons and Atkinson’s (1992) study on genetic risks, which shows how probabilistic information on Duchenne disease is pragmatically translated to everyday categories. Concerning e-health information on genetics, Schaffer et al. (2008: 157) state that:

mothers and other e-health users are not simply consumers of biomedical knowledge; rather, they are creative agents who produce not only specific forms of biomedical knowledge but also specific forms of genetic citizenship and related ethics.

On the other hand, Shostak et al. (2009) show that in questionnaire research, most respondents attribute illnesses to genetic make-up, suggesting a reproduction of professional discourse. Our own prior research on noise annoyance revealed that people both reproduce expert explanations and go against them (Bröer 2007, 2008, Kroesen and Bröer 2009).

What we need, then, is a theoretical basis to systematically investigate the relationship between ‘modern medicine and the lay populace’ (Williams and Calnan 1996: 1609). Williams and Calnan argue that researchers working in a Foucauldian framework too easily assume that the dominant discourse and its production of subjectivity is met with passive acceptance. They claim that a ‘critical distance is beginning to open up’ (Williams and Calnan 1996: 1617), informed by risk and reflexivity, growing access to information and the reskilling of citizens. Risk and health-related social movements testify to this (for example, Brown et al. 2004).

Discourse resonance

The different possible relations between a dominant public discourse and personal discourse are systematised in the resonance model (Bröer 2007, Bröer and Duyvendak 2009). Resonance – meaning echo or repercussion – points to traces of public discourse in personal utterance. The model is based on a discourse theory of the construction of meaning and discourse analysis methodology (Howarth 2000, Potter 2004, Wetherell et al. 2001). It specifies one of the power effects of discourse: it delineates what can be said or thought concerning a specific issue. The model specifies three possible relationships between public and personal discourse:

1 Consonance: people adopt the dominant public discourse.
2 Dissonance: people adopt parts of the dominant discourse, challenge its other parts and modify it when applying it to their own lives.
3 Autonomy: people construct meaning without using or rejecting the dominant discourse.
ADHD

ADHD seems to comprise lack of attention and impulsivity among other behaviours. Medical research claims that full-blown adult ADHD persists in about 15% of the cases reported among children, while 50% are thought to be in partial remission (Faraone et al. 2006). Epidemiological studies estimate ADHD prevalence in adults to be 2–5% in Europe (Kooij et al. 2010) and 1–5% in The Netherlands (Buitelaar 2001). ADHD in adults is most commonly treated with stimulant medications (methylphenidate and dexamphetamine) and atomoxetine (Kooij et al. 2010).

ADHD has been approached by social scientists regularly (Conrad 1976, Danforth and Navarro 2001, Malarcida 2004, Singh 2002, 2004, 2008, 2011). The history of this label can be traced to 19th century discussions on imbecility (Rafalovich 2001) and it is close to other more recent labels such as hyperkinesis, minimal brain damage and attention deficit disorder (ADD) (Singh 2002). Conrad and Potter (2000) discuss the emergence of adult ADHD in relation to versions of the Diagnostic and Statistical Manual of Mental Disorders. With DSM-IV (American Psychiatric Association 1994) it became possible to diagnose adults with ADHD if they had symptoms as children before the age of seven. Researchers, concerned individuals and pressure groups thus shifted their emphasis from hyperactivity in children to inattention in adults, which partly concurs with the shift in focus from ADHD to ADD. Adult ADHD can thus be seen as a case of diagnostic expansion (Conrad 2007, Conrad and Potter 2000). According to Conrad (2007: 64), the issue for adults is:

performance not behaviour: ... individuals feel that they could/should be doing better and they seek help in improving their performance. The ADHD diagnosis provides a medical explanation for their underperformance.

Medication such as Ritalin helps adults perform. Together, the availability of medication and the performance discourse make adults responsible for their biophysical functioning. This, Conrad argues, bends attention away from hyperactivity as a problem that arises from social organisation.

Ilina Singh’s research on children with ADHD and their parents shows that mothers adopt arguments of brain functioning to explain their children’s behaviour, though this does not relieve them of their traditional mothering roles. Instead, ‘the brain-blame narrative contains, supports and reconstitutes opportunities for mother blame’ (Singh 2004: 1204). As for the children, Singh emphasises that their self-understanding does not fully depend on medication and explanation of their conduct in terms of brain functioning. At least ‘children in this study did not appear to believe that they could have “bad brains” without being bad themselves’ (Singh 2007: 177). In short, Singh demonstrates that professional knowledge enters daily life without driving out other ideologies. Recently, Singh (2011) has shown how ADHD and specific interactional concerns, differing between cultures, intertwine.
In their examination of everyday talk about hyperactivity, Danforth and Navarro (2001) point to five different discourses that draw on both biomedical and school practices. Two discourses uncritically reproduce the school and medical discourses, while three partly reproduce and partly criticise them. This again questions any simple disciplining effect of a particular form of knowledge, be it biomedical or otherwise.

**Q-method**

Q-methodology originates in psychology and political science and has been adequately documented elsewhere (Brown 1980, Van Exel and de Graaf 2005, Watts and Stenner 2005). It has been applied to health research (Brown 1996, Dennis 1986, Stenner et al. 2000, Van Exel et al. 2006). In Q-method, subjectivity is assessed as a whole or a Gestalt. This is similar to interpretive social science methods, notably narrative analysis. Q-method differs from naturalistic interpretive approaches by asking its participants to perform a quasi-experimental sorting task: people rank statements, for example from ‘completely agree’ to ‘completely disagree’. The statements are not ranked separately, but in relation to each other. These statements come from everyday communication. Q-methodology therefore invites participants to position themselves in an existing discursive field.

The ranking of statements in relation to each other is central to this method; in this it differs from survey methodology where statements are assessed one by one. Given a set of 50 statements, for example, this amounts to \((50)\times(50-1)\times(1/2) = 1225\) separate judgments. The meaning of any one statement is constructed in relation to all the others.

The result of this ranking exercise is a snapshot of an individual’s views on a particular issue. Next, one can look for similarities between individuals or Q-sorts using factor analysis. This correlates individuals and not single items. The result is a number of factors or types of personal discourse. Interpretation of factors is then based on: (i) the statements that make up the factor, (ii) the participants’ own explanations of their ranking choices, and (iii) a knowledge of the field in which the statements were collected. Q-methodology thus involves both interpretive and statistical techniques.

Data collection using the Q-method basically involves the following steps:

1. Identify basic statements in public discourse.
2. Ask participants to order the statements in terms of (dis)agreement.
3. Statistically construct commonalities in how participants order the statements.

Note that, although statements originate in public discourse, people can rearrange these statements in an infinite number of ways.

*The public discourse*

We first need to delineate the Dutch public discourse on ADHD. The second author gathered a broad range of statements from different sources: 12 adults interviewed twice (structured interviews and open life-history interviews), 39 internet pages, 20 forum discussions and 29 blogs. To ensure inclusion of all different viewpoints on ADHD, we explicitly searched for uncommon utterances. Our sources also included seven information leaflets, eight books and 19 newspaper items. Findings on the Dutch public discourse have been reported elsewhere (Heerings 2009) and figure only as input here. Q-method was not used to delineate the public discourse, which was done through thematic content analysis (Hsieh and Shannon 2005).

In a nutshell, the Dutch public discourse on ADHD contains neurobiological, psychological and sociological definitions of the condition. The neurobiological definition
locates the aetiology of ADHD in the brain. The psychological argument focuses primarily on behaviour. Psychoanalytic arguments are also present, for example when experts refer to ‘inner conflicts’ as a source of hyperactivity. Sociological definitions stress that people with ADHD are thus labelled since they do not fit into modern society. Alongside these explanations for problematic conduct, we encounter statements on the advantages of hyperactivity, such as ‘creativity’. On the margins of the Dutch public discourse, we find ‘alternative’ or spiritual definitions of ADHD. Here, one claim is that people with ADHD are particularly sensitive.

In the Dutch public discourse on ADHD (Figure 1), neurobiological claims are central: almost all other claims, at least in part, refer to them. Psychological and sociological claims are also well-established; creativity is often mentioned while references to spirituality are less common. The structure fully fits what Hajer (1995) calls a discourse coalition: the existence of a central node, to which even opposing arguments refer. The structure of the Dutch ADHD discourse is similar to Rose’s description of the British one. But its content differs somewhat as there is hardly any mention in Rose of spirituality or advantages.

Dutch public discourse contains 192 different statements on ADHD. We made a selection which has to represent all the above-mentioned types: neurobiology, psychology, and so on. Though all types must be represented, it does not matter if they are represented by the same number of statements. If statements with one of the types constituted subtypes, we included statements representing these subtypes too. This was done in a number of separate sessions in which we individually and collectively compared different categorisations and samples. We tested the Q-sample for inclusiveness with five respondents, which led to minor adjustments. In the end, the following 54 statements were chosen (how they are positioned below is irrelevant):

Statements representing the public discourse on ADHD in The Netherlands:
1 The most significant features of ADHD are lifelong problems with attention or concentration, difficulty organising, impulsivity and hyperactivity.
2 ADHD is a neurobiological disorder. It has to do with being biologically different on the level of the brain. This ‘being different’ is expressed in behaviour.
3 ADHD is a coin with two sides: special talents and limitations.
4 When you have ADHD you are also highly sensitive.
5 ADHD is a manifestation of New Age children.
6 ADHD is more than a benign variety of behaviour. ADHD’s features are often so penetrating that they impede one’s own and other people’s functioning, at home, at school, at work and in leisure.
People with ADHD are not all the same, it can manifest itself in numerous ways.

ADHD is a disorder.

ADHD is the problematic way my brain works.

ADHD is just a type of personality; people with ADHD are only a bit different from others.

ADHD is not an illness, but something that is part of me and which makes me special.

I see ADHD as a gift.

I really suffer from my ADHD.

I don’t have to be ashamed anymore because I know what caused all those troubles.

ADHD is something of the present.

ADHD is not a disorder, the world and its greed and materialism are a disorder.

In the persistent search of a way to be victimised, ADHD is a welcome label for many people. In many cases the label is justified, but often it is a search for a scapegoat.

People with ADHD are sometimes enslaved by their failing neurobiological system: they want to change, but they cannot.

ADHD comes in different shapes and sizes. One can be troubled by it in many ways, or one isn’t troubled by it and benefits instead, for example, from creativity.

In our search for uniformity and control, a part of the individuality that could have become a great gift for humankind is destroyed by the diagnosis and treatment of ADHD.

Not treating ADHD in many cases leads to severe disruption.

By knowing one has ADHD one can look for solutions for doing things differently.

Adults can control their ADHD by gaining awareness of their strengths and weaknesses.

Medication is the basis for treating ADHD.

The world is not really ADHD-friendly. It is time to understand that not everyone’s head works the same way. Understanding comes not only from friends and family but from the wider environment.

It is very important for people with ADHD to learn to use their strengths and special talents.

Medication helps you to make use of your gift.

Self-knowledge is an important step in turning the disorder into an advantage.

By changing your diet you can significantly reduce the symptoms of ADHD.

Through Bach remedies and Indigo remedies, Children of the New Age can function well again.

There are plants, minerals and animal products that can induce the symptoms of ADHD. As a homeopathic remedy these substances can reduce the symptoms of ADHD.

ADHD can work as an advantage or as a disadvantage. Most of the time it is up to you.

By taking medication, people with ADHD can get their lives under control and have the peace and attention to look for other forms of treatment.

Treatment of ADHD with medication comes down to compulsively making someone psychotic by chronically administering high doses of strong antipsychotics.

With disorders such as ADHD, some parts of the brain do not work well. With neurofeedback patients can train their brain in such a way that they can end their disorders.

Changing thinking patterns can help in making ADHD manageable.

Hyperactive individuals can become calmer through certain kinds of stones.

Holistic healing through which the person with ADHD no longer rejects himself and his spiritual being is a way to help a person with ADHD.

People with ADHD benefit from practising meditation.

There is no consensus yet about the causes of ADHD.
ADHD is a diagnosis based on descriptions of behaviour; it says nothing about the cause of this behaviour.

ADHD has existed for a long time; it is not a disease of the present.

The fact that something shows up on a brain scan does not mean that ADHD is caused by a brain disorder.

ADHD is a neurobiological condition. ADHD has a biological cause that is situated in the brain.

The demands of modern society on things like concentration and discipline are getting stronger and stronger. Because of this, there is ever less room for people who are ‘too active’. No wonder ADHD is increasingly being diagnosed.

In a hunting society, people with ADHD are advantaged by their wide view, sense of thrill and ability to decide and act quickly. ADHD is a disadvantage only in modern society.

My problems with ADHD mainly arise from other people’s issues with it.

ADHD can be caused by a sustained deficiency of the right nutrients.

Social factors such as upbringing in an unstable family can cause ADHD.

People with ADHD are distracted because they constantly search for pleasure.

ADHD is caused by an inflammatory or immune response. What classic psychiatry considers as causes are just a few possible triggering factors that deregulate the immune system.

My problems are caused by changing sensitivity and consciousness of soul.

I think that pharmaceutical junk – Concerta, Ritalin, etc. – is very dangerous.

You can give me half a pharmacy of drugs that will take away the symptoms, but not the causes.

Participants order the statements

In an online form, participants were asked to rank these statements in terms of agreement (+6 completely agree to −6 completely disagree). The separate statements appeared on screen where participants could enter them into a field between +6 and −6 (for a demo of the procedure see http://hackert.biz/flashq/demo/ last accessed 26 March 2012).

After ranking, respondents elaborated on their extreme (±6) statements. A number of respondents stopped filling in the form as they were unable to keep focused.

To give an example: imagine that a respondent agrees with neurobiological arguments about ADHD. This would mean he/she strongly agrees with statements 2, 9, 18, 25, 45 (+6 or +5). In line with the resonance model, the dominance of a certain discourse is also apparent when it figures strongly as a negative (−6, −5). A respondent could also strongly agree with both sociological and neurobiological arguments at the same time. Q-method presents the ingredients of a discourse without imposing it.

We included adults diagnosed with ADHD and found through internet patient forums, social media communities, patient organisations, mental health organisations and personal contacts. Respondents were sampled in this manner to include as many different viewpoints as possible. This means that the results represent the kind of discourses one can find among adults, not their numerical distribution.

Between April and July 2010, 145 adults filled in the online Q-questionnaire. Respondents were aged between 19 and 62, with a mean age of 38; 24% were male (n = 35), 76% female (n = 110). A total of 93% had been diagnosed by a professional (n = 135), almost all as adults. Furthermore, 15% (n = 22) had received no treatment for ADHD, 72% (n = 105) took medication, 53% (n = 77) had recently seen a health professional (that is, a psychologist, specialised nurse or coach), 6% (n = 8) had
received alternative treatment, and 5% \((n = 7)\) stated that their situation differed from the described treatment possibilities.

**Personal discourses**

Below, we present five discourses on ADHD constructed with the Q-method. In all, 145 adults filled in the Q-sort and often added extensive comments. Technically, the five different discourses are the main factors derived from centroid factor analysis using varimax rotation and PQMethod software (what this entails is described in Watts and Stenner 2005). In every factor, each statement has a certain rank (see Appendix 1 for the ranking of all statements in all factors).

As is usual in Q-studies, we included only factors loading on more than two subjects and having an eigenvalue greater than 1. We only included those Q-sorts that load on one factor, with a loading of 0.4 or higher. Based on these criteria, the five-factor solution included 76 Q-sorts. Of these 55 Q-sorts loaded on more than one factor, while 14 Q-sorts did not load significantly. The five factors together explain 53% of the variance. Note that this only holds for the theoretically constructed sample and not for the population of all adults with ADHD. We complemented the interpretation of factors with people’s comments on their own rankings. We asked respondents to explain their choices (+6, −6); they often provided thorough accounts.

There is a strong correlation between all discourses (see Table 1). But this does not mean that participants agree on most statements. On the contrary, every discourse or factor contains 17 to seven statements that are ranked in a specific way only in that factor. Only one statement (S44) is ranked the same way in all five factors. In other words, there are significant and subtle differences between the factors. We now look at the different discourse in more qualitative terms to find out what they are about. Later, we return to the question of an overlap or correlation between the factors.

In describing the different types of personal discourse (factors), we refer to the statements and their rank between brackets. For example, \((S13:6)\) means that statement 13 is ranked +6, which means complete agreement. Through Q-analysis, in every factor each statement has a certain rank (see Appendix S1 in Supporting Information in the online version of this article).

<table>
<thead>
<tr>
<th>Discourse</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sorts loading significantly</td>
<td>77</td>
<td>32</td>
<td>36</td>
<td>37</td>
<td>12</td>
</tr>
<tr>
<td>Distinguishing statements</td>
<td>17</td>
<td>9</td>
<td>12</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Explained variance</td>
<td>20</td>
<td>9</td>
<td>10</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Cumulative explained variance</td>
<td>20</td>
<td>29</td>
<td>39</td>
<td>49</td>
<td>53</td>
</tr>
<tr>
<td>Correlations among discourses</td>
<td>0.85</td>
<td>0.77</td>
<td>0.85</td>
<td>0.79</td>
<td>0.81</td>
</tr>
</tbody>
</table>

Table 1. *Descriptive statistics of the five discourse*
Enslaved by the brain

As crude as ‘enslaved’ may sound, this is the only discourse that supports the statement that people with ADHD are literally ‘slaves to their failing neurobiological systems’ (S18:5). This discourse emphasises the problematic, symptomatic and biological aspects of ADHD that cause distress and problems in various areas of life. One is ‘really distressed’ (S13:6) and seriously impaired (S6:6) for life (S1:5). The diagnosis itself is welcomed as a means to a solution (S23:5). While the latter statement ranks high in all five personal discourses, here the kind of problem and the kind of solution is more specific. ADHD is defined as a neurobiological disorder (S2:4; S18:5; S45:4); medication is important (S54:-6; S34:3; S25:2). This discourse is opposed to less negative interpretations of ADHD. It strongly refutes arguments referring to social causes (S50:-5; S15:-5; S16:-3; S17:-4) and doubts about medication (S35:-6; S54:-6). Like most of the other personal discourses, alternative and spiritual interpretations rank low. ADHD is a ‘real’ problem situated in neurochemical disfunctioning.

A number of rankings and associated comments shed light on this construct. One respondent (R62) remarked: ‘Brains are the foundation of behaviour, emotion, thinking etc., I am wired differently and therefore react differently’. This definition of ADHD as a neurological impairment is backed up with experiential evidence:

I believe that this is a neurological problem. Especially with regard to my own past and the many failed attempts to change patterns of thought to function better. After being diagnosed with ADHD and after taking medication, I see that I can break through my patterns of thought. (R128).

One respondent (R73) commented on statement 1 (on the symptoms of ADHD): ‘These are the problems I experience, corresponding with the DSM–IV’. Another respondent (R114) wrote: ‘I cannot keep up with society. I want to but I don’t succeed. All that noise in my head is so tiring’. Interestingly, this does not lead to the conclusion that something is wrong with ‘society’.

The advantages of ADHD

While the ‘enslaved by the brain’ discourse mentions only the problematic side of ADHD, discourse 2 includes its advantages. Knowing yourself is the way to turn the disorder into an advantage (S29:6). As statement 27 (+5) reads: ‘It is very important that someone with ADHD learns how to use one’s strong sides and special talents’. Problems are not denied, but seen as ‘one side of the coin’ (S3:5; S24:4). One may be troubled by ADHD but can also benefit from heightened creativity (S20:4). ADHD is seen as a neurological condition (S45:5; S2:2) which can in part be checked through medication (S34:4; S25:1). Nevertheless, people with ADHD are not determined by neurological processes (S18:0); they can manage and control the condition (S24:4). Medication ‘helps you to use your gift’ (S28:2). The ‘advantages’ discourse endorses medication, but as part of a more positive and self-determined way of dealing with hyperactivity. Alternative and holistic approaches are strongly opposed.

In comments associated with this construct, respondents stressed their trust in mainstream science. Medication is modestly supported (S34:4; S25:0): ‘With medication I can further develop my talents’ (R1). Several people noted the beneficial aspects of hyperactivity. R60 stated:

It is my experience that I do benefit from ADHD, with the fast associational thinking I can make people laugh and come up with special creative projects. That I have difficulties
implementing these projects means that I need to find the right people. In fact, this is possible most of the time.

As R140 says, one has to be aware of one’s ‘personality’: ‘It is important to have a clear picture of your personality traits. Then you can better fit out your life and bring the positive sides to the fore’. Within this discourse, there is attention to the relationship between person and society. As R140 states: ‘As a bookkeeper (or something like that), it is much harder to live with ADHD than as an artist or scientist’. This sense of the contextual effect of ADHD also includes some sociological reasoning, though a more forceful stance in which ADHD is explained by social forces is not found here (S21, S26, S46:0/-1).

A societal problem
This discourse is similar to the two previous ones but adds ‘society’ as an explanation for problems associated with ADHD. There is complete agreement with statements 27 and 29: ‘It is very important that someone with ADHD learns how to use one’s strong sides and special talents’; and ‘Knowing yourself is the way to turn the disorder into an advantage’. The importance of the ADHD label in self-knowledge is expressed in S23 (+5): ‘By knowing one has ADHD one can look for solutions for doing things differently’. ADHD can be expressed in many ways (S7:5; S20:4). Problems are not denied (S1:4; S13:3) but seen as ‘one side of the coin’ (S3:5; S24:3).

This discourse differs from the others (except ‘advantages’) in emphasising society’s role in the problems faced by people with ADHD. ADHD characteristics have always been present (S15:-6) but the demands of present society make them problematic (S26:4; S46:2; S47:2). This was echoed in several comments: ‘That ADHD is named doesn’t mean it didn’t exist before’ (R76); ‘I think in a society with a much slower pace people with ADHD would function better’ (R138); ‘ADHD is more noticeable in current idiotic society ... ADHD used to be important, without them/us we would still be in bearskins’ (R93). The discourse does not endorse nor oppose radical criticism of society – ‘our drive towards conformity and control ... destroys individuality’ (S21:0). It does firmly reject more alternative explanations and treatments (S5:-6; S31:-5; S49:-5; S50:-5).

This discourse also opposes classifying ADHD as a disorder (S8:-2; S11:3). While the neurobiological aspects of ADHD are not denied (S2:1; S9:0; S45:0), they are hardly relevant here. The use of psychiatric medication is mildly opposed (S25:-2; S34:0), while statements expressing strong anti-psycho-pharmaceutical opinions are not as strongly opposed as they are in the other discourses (S54:-1; S35:-3). Several comments elaborate on this. R93 writes:

I refuse to have the psychiatric disorder ADHD, just because it happens to be in the DSM-IV doesn’t make it a disorder ... the line between what is normal and what is a disorder is made up by society and is thus artificial.

R59 states: ‘I see ADHD as a characteristic. Not a disorder ... but a characteristic that gives little advantage in current society’.

The neutral position of S14 (0) – ‘I don’t have to be ashamed any more because now I know what causes my problems’ – distinguishes this discourse: in all the others, it ranks high. Here, shame is not an issue but social categorising is, as R93 puts it: ‘it is very stigmatising to name ADHD a psychiatric disorder’. While the ADHD label itself is not problematic, viewing it as a psychiatric disorder is.
No suffering and a hint of spirituality

This discourse is similar to ‘advantages’. ADHD has negative as well as positive sides that can be developed once you know about the condition (S23:6; S27:6; S24:5; S20:5; S29:5). As in discourses 1 and 2, we see neurobiological definitions of ADHD and medication (S45:4; S2:2), though not in the sense that one is enslaved by the condition (S18:0). This is the only discourse that does not endorse the statement that one is suffering from ADHD (S13:0). Using social factors to explain ADHD is refuted (S50:-6; S15:-5). Negative remarks about medication score very low (S35:-6; S54:-4).

This discourse is furthermore distinguished by its slight openness to holistic and alternative treatments. Meditation is mildly supported (S40:1). Holistic healing, the therapeutic use of stones and homeopathic remedies are not (strongly) rejected (S39 and S38:0; S32:-1) whereas the other discourses all rank these statements (very) negatively. Even the statement that ADHD is an expression of Children of the New Age is less strongly rejected (S5:-3). Openness towards spirituality is thus a defining characteristic of this discourse.

In the comments, respondents vividly describe the ‘positive sides of ADHD’: people with ADHD ‘bring colour to the world’ (R10). ‘You win a medal and you will wear it, but you know that has two sides’ (R116). With medication, people are ‘able to use their gifts’ (S28:2). ADHD is not a disease but ‘something which is part of me’ (S11:2), which can be developed by ‘a coach who really confronts you with what you are doing, mirroring your behaviour and who tries to make you look at things differently’ (R102).

Reducing shame

This discourse stresses the importance of being diagnosed with ADHD, since this offers an explanation for the problems one faces and reduces shame (S14:6). Several respondents expanded on this, for example R30: ‘It was an enormous relief to me, to finally know why I was “different”’. But being diagnosed with ADHD does not easily lead to solutions, seen in the relatively low score of S23 (+3) which distinguishes this discourse. ADHD comes to the fore as ‘a coin with two sides’ (S3:5). Its problematic aspects are emphasised (S6:5; S1:4; S13:3), while learning how to make use of its positive sides is important in overcoming difficulties (S27:6). Sociological explanations are opposed or seen as irrelevant (S16:-4; S26:0; S46:0; S47:0). As in discourse 3, neurobiological aspects of ADHD are deemed unimportant (S18:0; S44:0; S45:2). There is slight opposition to medication as the basis of treatment (S25:-2; S28:-2; S34:0), while changing one’s way of thinking is important to make ADHD manageable (S37:4). These considerations may favourably dispose individuals towards psychological treatments such as cognitive behavioural therapy (CBT). A respondent loading high on this discourse states: ‘Lots of people with ADHD, myself included, have a negative thought pattern. Learning how to control that, for instance with CBT, can be very beneficial’.

The public and the personal discourse

Neurobiological definitions of ADHD dominate the Dutch public discourse on ADHD. Different arguments, from psychology and sociology, spiritual arguments and arguments about the advantages of ADHD are present but they are always related to neurobiology. In that sense, neurobiology itself even depends on other, older arguments. We examined how adults with ADHD relate to this public discourse. Using the Q-method, we constructed five different discourses among Dutch adults who have adopted the ADHD label: ‘enslaved by the brain’, ‘advantages’, ‘a societal problem’, ‘no suffering’ and ‘reducing shame’. Alongside neurological arguments, we found psychological, sociological and holistic arguments to
inform these personal discourses. Rose stresses neurochemical discourse; Conrad focuses on performance. We encountered both in our research, as well as a range of other concerns. Alongside the neurochemical self, we find ideas about shame and social context, holistic healing and special personality traits. There is no central idea that unites and dominates the five personal discourses.

Holistic and spiritual arguments attract by far the most criticism in the sense that they are most often strongly dismissed (−5, −6) in the Q-sorting exercise. But even these arguments are at least mildly supported in one discourse. We also see that critical arguments themselves become objects of criticism: three of the discourses explicitly oppose the critique of medication and sociological arguments about ADHD. We interpret this as the relative strength of oppositional arguments: one has to deal with critical remarks.

No single definition is shared by all discourses, but there is considerable overlap between some. We saw this in the statistical correlation between the discourses (Table 1) and in the content of them. Every ‘next’ discourse is in part a repetition of the one before. This discursive structure is known as family resemblance. Unlike the structure of the dominant public discourse, personal discourse has no centre. A rough approximation of its structure is shown in Figure 2.

Colonisation of subjectivity therefore does not feature. Dominant notions resonate, but people reassemble the public discourse and construct diverse personal discursive spaces. This is in line with research on ‘hyper talk’ among the general public, which has shown that although dominant notions of ADHD resurface there, they do so in a modified form (Danforth and Navarro 2001). Singh (2004, 2011), too, analyses the differential uptake of professional discourse among parents and children with ADHD. Schaffer et al. (2008: 157) make similar observations regarding genetics. In general, this seems to support a reflexivity theory of health and illness (Williams and Calnan 1996). Recently, Pickersgill et al. (2011) also found that neurobiology is taken up differentially. People show an interest in and attribute general significance to neurobiology but do not exclusively explain behaviour in such terms.

Our findings, like those of Pickersgill et al. (2011) suggest that Rose (2007) overstretched his argument when he wrote that we increasingly understand ourselves in biological terms. Where neurobiology is invoked, this is done in different ways. In the ‘enslaved by the brain’ and ‘reducing shame’ discourses, neurobiology figures as an explanation or excuse. But in the ‘advantages’ perspective, neurology and medication are linked to self-control. This would seem to give credence to claims of increasing governmentality: people have internalised a combination of self-regulation, responsibility and ‘brain talk’ (visible in the ‘advantages’ and ‘no suffering’ discourses). But the other personal discourses also stress self-regulation without supporting neurobiology and medication.
Conrad’s claim that the diagnostic expansion of ADHD to adults furnishes a ‘medical excuse’ and directs ‘attention away from social forces to biogenetic ones and shifts blame from the person to the body’ (Conrad 2007: 64) might also be overstated. Nevertheless, we did find support for Conrad’s thesis that the ADHD label is used to handle bad performance at work. The ADHD diagnosis can be used as an alternative source of self-esteem and to one’s own advantage; a person with ADHD can be perceived as someone with special talents such as ‘creativity’. These arguments can be seen as a medicalisation of problems with self-esteem arising in a meritocracy (Tonkens and Swierstra 2010, Young 1958). A handicap is redefined as a talent and as an excuse. Nevertheless, the drive towards performance is not all-consuming; acceptance is part of the personal discourse as well. So while performance is a major issue it does not structure all personal discourses.

Why – in contrast to our previous findings – did public discourse not colonise subjectivity? First of all, the public discourse on ADHD in The Netherlands itself is quite inclusive. The Netherlands has a tradition of debate and dissent over mental health issues, which creates room for discursive diversity. Mental health professionals treating adults with ADHD do not fully align around the neurobiological argument. While neurobiology has recently become central, other arguments are still strongly represented. The public discourse popularises certain claims about neurobiology, but also reproduces paradigms that have been dominant earlier. This preserves significant deliberative space for people to position themselves.

More importantly, this leads to the question how we, citizens in countries with a large and differentiated public realm, come to define our health. Where, when and how do we learn about our bodies and ourselves? Indeed, a learning or socialisation perspective is crucial here. Individual trouble needs to be (re)stated in socially accepted terms. But this is far from a pre-defined sick role. Even among the group of adults who adhere to the label of ADHD, large variation is to be found.

Furthermore, as Pickersgill et al. (2011) state, one has to ask in which situations neurobiology is relevant. Here, it is the research itself which presents neurobiology to people, but in a way that leaves them enough space to remain ignorant. For adults with ADHD, neurobiology can be relevant in connection to performance, to identity, to legitimacy and to shame, at least. It further seems that the success of neurobiology-based treatment is crucial. If medication helps, people most likely support it more strongly than when it fails, we suspect. But since chronic conditions and mental health problems tend to remain to some degree, patients move through different paradigms. Therefore, what we need and are already starting is longitudinal research: investigating the situations in which health definitions are learned, used and transformed.

Finally, instead of claiming there is a general trend towards reflexivity or discipline, we thus have to attend to the specific cases at hand. While our research on the health effects of electromagnetic fields and noise annoyance revealed strong colonising effects, there is discursive space for hyperactive adults to not include neurobiology in their own definitions of hyperactivity.

Address for correspondence: Christian Bröer, Department of Sociology and Cultural Anthropology, University of Amsterdam, Spinhuis, Oudezijds Achterburgwal 185, 012 DK Amsterdam, The Netherlands
e-mail: c.broer@uva.nl

© 2012 The Authors
Sociology of Health & Illness © 2012 Foundation for the Sociology of Health & Illness/Blackwell Publishing Ltd
Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Ranking of statements per discourse

Please note: Wiley Blackwell are not responsible for the content or functionality of any supporting materials supplied by the authors. Any queries (other than missing material) should be directed to the corresponding author for the article.

References


Dumit, J. (2006) Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses, Social Science & Medicine, 62, 3, 577–90.


Public and private discourse on adults with ADHD


