


# Youths' and Adults' Stories Related to the Background for ADHD Assessment

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## Abstract

In connection with a study relating to the diagnosing of Attention Deficit/Hyperactivity Disorder (ADHD), youths and adults represent a particularly interesting group, partly because they have lived a relatively long time *with* the condition but *without* the diagnosis. In this article, I am focusing particularly on the life stories of youths and adults *before* they were referred for an ADHD assessment. A narrative analysis of a body of empirical data material shows that the subjects' stories about the background for their referral are dominated by three themes: substantial *health-related disorders and problems*, *diffuse sensations* that “something” was wrong, and experiences relating to their *identification* with the diagnosis. The study shows that most of the respondents had been in contact with their regular general practitioner (GP)—and in many cases had tried out various diagnoses and treatments—long before the question of ADHD was raised.

## Keywords

Attention Deficit/Hyperactivity Disorder (ADHD), life stories, key events, identification, health issues

Youths and adults stand out in several respects as a particularly interesting age group in an investigation of the diagnosing of Attention Deficit/Hyperactivity Disorder (ADHD). First, the diagnosis is a rather recent one. The term *ADHD* did not appear in the diagnostic manuals until the end of the 1980s.<sup>1</sup> Furthermore, the medical definition of the condition has, traditionally, primarily been concerned with children. The description of the clinical symptoms in the diagnostic manuals is still colored by this tradition (The Norwegian Health Directorate, 2007). It was not until 1994 that the criteria for the diagnosis were altered, so that ADHD was defined as a lifelong condition. As a result of this, it became possible for adults to be diagnosed with ADHD. In 2005, adults in Norway were given the same access as children and youths to medical treatment with psychostimulants. The access to an effective pharmacological treatment may have contributed to the diagnostic assessment appearing more meaningful and attractive, which in turn may have contributed to a rise in the number of ADHD assessments among youths and adults.

Adults (aged 19 years or older), thus, constitute a relatively new group among those who can be diagnosed with ADHD. In line with the immediate consequences of the above-mentioned changes, it turns out that the largest relative growth in the number of Norwegian users of ADHD medication between 2004 and 2014 has taken place in the age group “19 years or older.”<sup>2</sup> The remarkable thing about those referred for a diagnostic assessment as youths or adults is that while they have already lived for a long time *with* this condition, they have lived *without* the ADHD diagnosis.

As suggested above, there are several plausible explanations for this development. Similarly, there are theories on the interaction between the diagnostic categories and the people within a society that supply adequate explanations of such a development (Hacking, 2004; Latour, 1987).<sup>3</sup> Newer empirical research has also shed more light on different aspects of the diagnostic assessment of adults. This research includes descriptions of typical challenges for adults with ADHD, and underlines the importance of the diagnostic assessment and treatment for the adults' self-image, and their ability to handle these challenges (Fleischmann & Miller, 2013). It has been documented that the same symptoms and challenges are registered in the various life phases both in North America and Europe (Brod, Pohlman, Lasser, & Hodgins, 2012). It has also been proven that students may struggle to handle their “medicated selves” (Loe & Cuttino, 2008), that adults may learn how to take advantage of their ADHD idiosyncrasies in a positive manner (Fleischmann & Fleischmann, 2012), and that it seems difficult to develop an effective test or method to uncover instances of misdiagnosis (Musso, Hill, Barker, Pella, & Gouvier, 2014). It is, however, harder to come by empirical investigations that help describe specific events and courses of events in the individual

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**Table 1.** Respondents' Participation in Work/Education.

Not on sick leave/disability pension				On sick leave/disability pension			
Pupil/student full-time		Working full-time		50%-60%		100%	
Informant	Diag.	Informant	Diag.	Informant	Diag.	Informant	Diag.
Bjørn (14)	Yes	Ida (42)	No	Mariann (33)	Yes	Emilie (34)	Yes
Anders (14)	Yes	Carl (23)	No	Peter (53)	Yes	Geir (23)	Yes
Fanny (17)	Yes	Daniel (19)	Yes	Hanna (40)	No	June (30)	Yes
Nora (33)	Yes					Kari (28)	Yes
						Linda (46)	Yes
						Oda (57)	Yes
						Rigmor (41)	Yes
						Sina (34)	Yes
						Therese (19)	No

processes of youths and adults, preceding and leading up to the diagnostic ADHD assessments. Among the questions that are especially salient for further attention are

- When and how have any symptoms of the condition manifested in earlier stages of life?
- In what way were the relevant symptoms and challenges perceived and handled?
- How did the suspicion of ADHD become relevant, and what happened after?

In my doctoral dissertation in sociology, I have previously examined various aspects of youths' and adults' everyday life and self-understanding *before* and *after* the diagnostic assessment of ADHD (Hannås, 2010). This dissertation is based on a comprehensive qualitative study. In this article, I would like to—based on empirical material from the same study—focus especially on particular experiences from the histories of youths and adults *before* they were referred for ADHD assessment. The main research question is as follows:

**Research Question 1:** What is the background for youths and adults being assessed for ADHD?

## Methodological and Analytical Approach

The referred study is based on semi-structured interviews. This is a form of interviews characterized by open-ended questions, where the informants are given the opportunity to raise their own topics during the conversations. Both this interview form—explicitly and implicitly encouraging the sharing of personal experiences—and the subsequent analysis of the narratives in the autobiographical stories are strongly influenced by a narrative approach to the research question (Briggs, 1986; Riessman, 1993).

In collaboration with the adult psychiatric and children and youth psychiatric clinics, the public educational psychology

service and the Norwegian interest organization for ADHD, 19 respondents aged 14 to 57 years were recruited to the interview study. Two criteria were defined for participating in the study. First, the participants had to have been referred for a diagnostic ADHD assessment as youths or adults. Second, they should be aged 19 years or older. In three cases, I chose to include participants below the age of 19; specifically, two 14-year-olds and one 17-year-old. This was done at the request from the psychologists that helped recruit participants, as they felt that these youths would be well suited for participation in the study. The respondent group is comprised of 10 participants who had already completed their diagnostic assessment some time (on average about 2.5 years) before I interviewed them. These participants were interviewed once each. The remaining 9 participants were referred for ADHD assessment at the beginning of the interview study. These participants were interviewed both before and after their diagnostic assessments.<sup>4</sup> In the analysis, the data material is handled as a whole, with no distinction between the two sub-groups of participants. The interview study spanned over a period of about 1½ years. At the time of completion, 15 of the 19 participants had been diagnosed with ADHD (see Table 1). One participant (Ida, 42) had her suspicion of ADHD disproved by her diagnostic assessment. Another (Carl, 23) elected to abort the assessment because it was too problematic to carry it out during working hours. A third (Hanna, 40) was still waiting for the final conclusion of her assessment. Finally, a fourth (Therese, 19) had asked for an assessment to get rid of an ADHD diagnosis she had had for several years; an effort that proved successful. The analysis in the study is conducted on the data material in its entirety, that is, all of the interviews with everyone of the 19 informants.

All of the interviews were audio-taped. The recordings have been transcribed into texts where other forms of meaningful expression, for example, gestures, pauses, intonation, and so on, are indicated as well. The empirical material consists of 33 interviews, each lasting between 1½ and 2½ hr. In addition, an interview log-book has been kept, and notes

taken from individual telephone conversations, text messages, and emails from the participants. These notes have supported the processing of the data material, which was conducted by the author. All of the participants have been supplied the results of this processing, and were invited to respond to the presentation of the data before publishing. Several participants replied that they felt represented correctly. None replied with critical comments or objections to the presentations.

The narrative approach upon which the study was founded was clearly reflected in the transcribed texts. The transcriptions showed that each interview more or less consisted of an array of autobiographical narratives of shorter or longer duration. The narratives represented various personal experiences that referred to specific events—or sequences of events—at different times or phases in the lives of the individuals. Most of the narratives were easy to identify, in the sense that they, for example, had a clear beginning and a marked ending. This was, among other things, manifested through different forms of “entrance and exit talk” (Riessman, 1993, p. 58). All the narratives were characterized by the common overall theme of the conversations: “life with ADHD—before and after the diagnostic assessment,” a theme that the participants had been made familiar with prior to the interviews. This contributed to connecting different narratives within each interview to a personal life story.

To gain an overview of the contents of the transcribed material, the different narratives in the 19 life stories were first identified and classified using different codes. These codes were not pre-defined, but rather created as needed in the course of the classification process. After coding the whole raw material, I was left with 26 different codes. These codes had been labeled according to the actual content or plot in the narratives, for example, “movies/TV,” “brain damage,” “medication,” “clutter,” “different,” “conversations,” “distress,” “school,” “work,” “friends,” “family,” and so on.

In actual life, different events and actions follow each other in chronological order. Over time, a string of such happenings may create—or seem to create—a certain course of events. The connections between the various happenings encompassed in such a course of events are, in reality, not necessarily of a deterministic or causal character. Still, it turns out that “earlier happenings are, however, often retrospectively seen as a precondition for later happenings” (Horsdal, 1999, p. 123, author’s translation). In the autobiographical narratives, the “story,” however, does not follow the actual or chronological order of the specific happenings or “events.” In autobiographical narratives, especially those dealing with the important experiences in life, the author tends to continually move back and forth in time. The author digresses, and supplies personal commentary and evaluations in the course of the narrative (Riessman, 1993). To gain an overview of the chronological order of events, the coded narratives were systematized based on the actual time of the various events in the life stories.

The form of narrative causality described above contributed to some specific narratives from the time preceding the referral appearing, in retrospect, to constitute plausible explanations for the referrals for diagnostic assessment. In the same way, the narratives concerning the assessment and the result of this, appeared to be a natural explanation or consequence of the narratives concerning different sorts of difficulties and challenges.

After identifying which narratives functioned as reasons or explanations for the narratives regarding the referral, the empirical material was reduced by keeping these narratives, whereas the other narratives, in this context, could be eliminated from further analysis.

The remaining narratives were then systematized into different main categories and sub-groups, based on an analysis of the themes of the narratives. During this part of the analytical effort, one narrative could occasionally be placed several places at once. The final result of the analytical process uncovered three main themes emerging from the participants’ narratives of the background for their ADHD assessment.

Autobiographical narratives may, for several reasons, often deviate from the actual events they refer to. One partial explanation for this may be that the narratives are situated interpretations of earlier experiences, and that insights gleaned from later events may contribute to a retrospectively founded interpretation of earlier events. The narrative of one specific experience may, in this way, change from one situation to another (Horsdal, 1999). The autobiographical narratives, in other words, do not reveal the past the way it really was. On the contrary, they reflect the meaning which the authors at any given point in time—consciously or unconsciously—attribute to earlier events in their own lives. Even if they do not represent any sort of objective truth, the autobiographical narratives are still required to have some sort of credibility. One of the main requirements of the autobiographical narratives is a level of consistency that makes them appear—and be accepted by others—as trustworthy: “The historical truth of an individual’s account is not the primary issue. . . . ‘Trustworthiness’ not ‘truth’ is a key semantic difference: The latter assumes an objective reality, whereas the former moves the process into the social world” (Riessman, 1993, pp. 64-65).<sup>5</sup>

As pointed out before, there are weaknesses, too, associated with a narrative form of analysis. In this context, the advantage is the ability to take the narrative’s creation of meaning more into account in the analytical work than a more traditional coding and categorizing of the textual material would allow.<sup>6</sup> One of the main functions of a narrative is that, through both its form and its contents, it contributes to configuring or creating meaning in life (Horsdal, 1999). A more traditional approach to the textual material, “. . . by taking bits and pieces, snippets of a response out of context” (Riessman, 1993, p. 3) would reduce the ability to take into account the participants’ interpretations of meaning: “Precisely because they are essential meaning-making structures, narratives must

be preserved, not fractured, by investigators, who must respect respondents' ways of constructing meaning and analyze how it is accomplished" (Riessman, 1993, p. 4).

There is no single specific method or approach to narrative analysis. On the contrary, there is a range of different approaches to texts of a narrative character. Furthermore, narrative methods combine well with other forms of qualitative analyses (Riessman, 1993). As can be gleaned from the above description, I have combined elements from a traditional form of cross-sectional analysis (from Grounded Theory, cf. Glaser & Strauss, 1967), with elements of Labov's method for analysis of personal narratives, in the course of processing the empirical data.<sup>7</sup>

### Three Main Themes of the Autobiographical Narratives

The analysis showed that three main themes dominate the background narratives of the youths and adults. The first theme refers to various types of *health-related disorders and problems*. This is a main theme in 14 out of the 19 life stories. The second theme is a sort of *diffuse sensation* of not being quite like everyone else, and that "something" must be wrong. This is a main theme in 10 out of the 19 life stories. Last, the third main theme is *identification*. This theme covers the way the participants themselves, at a certain point, started identifying with the ADHD diagnosis. *Identification* is a main theme in every one of the 19 life stories. In 8 of the 19 life stories, both *health-related disorders and problems* and *diffuse sensations* show up as parallel main themes. In 2 of the life stories, *identification* is the sole main theme. In these cases, the participants emphasized that they had not experienced any specific difficulties or challenges prior to their referral for a formal ADHD assessment.

A more detailed presentation of the three main themes is given below. The in-text quotes are supplied as representative examples of how different aspects of the three main themes were expressed throughout the empirical material.

#### Health-Related Disorders and Problems

Health-related disorders and problems turned out to be a pronounced theme in 14 out of the 19 life stories. Common for these 14 life histories are the descriptions of longer periods of time characterized by various sorts of illness and health-related issues and problems. The analysis shows that, in most cases, the respondents' problems started a long time before an assessment for ADHD became a relevant question. The narratives include descriptions of numerous health-related issues, and the diverse consequences of these. In one respect, the narratives refer to the participants' personal experience of their own ailments, spanning a broad specter; from different somatic complaints like fever or pains, to problematic mood

swings and feelings of total exhaustion. A recurring experience in these narratives is spoken of as "hitting the wall" or "having a breakdown."

*Kari (28)*: So I had a—. I hit the wall, as they put it. . . . It was just that I couldn't, uh—both be a mother, and a housewife, and be a wife at the same time! . . . That was how I felt. At my lowest point. And then they [medical professionals] started with the manic depressive and all that sort of stuff. (Hannås, 2010, p. 100)

In another respect, the narratives refer to how other people, especially physicians and medical professionals, perceived, interpreted, and defined these challenges in different circumstances:

*Linda (46)*: I don't know if there's anything they haven't assessed me for, let me put it like that. . . . But there's been—yes, brain tumor and arthritis several times—and MS—and he [the regular GP] started talking about this ME and fibromyalgia. (Hannås, 2010, pp. 103-104)

Upon meeting with the health care services, the participants' issues have been interpreted as symptoms of several different disorders, but among the most frequently mentioned are depression, bipolar disorder, burnout syndrome, and chronic fatigue syndrome. Several of the participants have received other diagnoses, and tried different treatments, such as lithium, antidepressants, or tranquilizers, before being referred for ADHD assessment.

*June (30)*: Because, you know, I've had "type two bipolar," and I've had "borderline," and I've had "personality disorder," and then I've had—. Yeah, because every time I've been in contact with the psychiatrists, I've ended up with a new diagnosis. (Hannås, 2010, p. 109)

The participants often seem to have been skeptical toward—or disagreed with—the doctors' assessments. Several informants neglected to try out medication that they were prescribed based on diagnoses that they were basically skeptical of:

*Rigmor (41)*: I went to my regular GP. . . . he gave me happy pills. . . . I did *not* feel depressed. And I did *not* have any fear of going out for coffee or any of those things. . . . I did not take that medication. (Hannås, 2010, p. 121)

Others, like June (30), said that they had tried the prescribed medication, but rejected it as it did not do them any good: ". . . I said from the beginning that I wanted out of the lithium, because it didn't help my depressions" (Hannås, 2010, p. 109).

The first and foremost characteristics of the many stories of illness, however, are the comprehensive and dramatic consequences these health-related issues had for the individuals.



Periodically, they made the participants quite incapable of functioning adequately in everyday activities, both at home and at work. They were drained of energy, and consequently many had to take sick leaves. Several participants told they had been more or less bed-ridden—in some cases up to a full year.

An overview showing how many of the participants who ended up on sick leave or disability pension illustrates both the degree and the magnitude of their challenges tied to health-related issues. Table 1 gives an overview of the respondents' participation in education and work at the time when the interview study finished. The bracketed numbers following the names indicate the age of the informants at the beginning of the study. The columns marked "Diag." indicate who had or had not been diagnosed with ADHD by the end of the study.

Table 1 shows that 12 out of the 19 participants were either on sick leave or disability pension, and that 9 of them were completely out of education or work life. Furthermore, it shows that 7 out of the 19 informants were neither on sick leave nor disability pension. However, it should be pointed out that most of the participants who were neither on sick leave nor on disability pension (4 out of 7) were under education. As some of these participants also spoke of health-related problems, this might indicate that the educational system is more tolerant or flexible with regard to individual adaptation needs, compared with work life. It should also be noted that the table shows that just 3 out of the 19 participants were working full-time, and that 2 out of these 3 were among those who were not diagnosed with ADHD by the end of the study.<sup>8</sup>

### Diffuse Sensations

The majority, that is, 10 of the 19 life stories, contained narratives of various childhood experiences, circling the topic of being set apart and feeling different from other people. No analytical categories had been pre-defined before the study, and neither was this a theme that the participants were encouraged to illuminate in the course of the interviews, unless they broached the subject themselves. Still, diffuse sensations emerge as the second main theme of the narratives of the background for ADHD referral.

The recurring theme of these narratives is the diffuse, but nevertheless constant feelings in the participants that something had to be wrong with them. Many of these narratives start out with memories from early childhood. They may be tied to very different practical situations. The common denominator is the experience of being different, and coming up short—most often as a consequence of some sort of deviation or breach between their own or others' expectation (general norms) and their own social performance. In some narratives, this description is specified as difficulty controlling their own behavior in a socially acceptable way in certain situations or contexts. Typical of other narratives is that the respondents themselves do not really understand what it is they are doing

“wrong.” For example, Hanna (40) told me that she noticed a long time ago that others—interacting with her—tended to react with raised eyebrows or shrugs, and subsequently withdrawing from her; however, she had no idea why they did this. Hanna was one of several respondents who told me she had struggled to gain and keep friendships in the way her peers did, both in her childhood and her youth. When Hanna started telling me about the background for finally being referred for ADHD assessment, she began her story thus:

*Hanna (40):* I was seriously starting to wonder if I was retarded, you know! . . . And the way people reacted to me, I was wondering: Is my head muddled? . . . Am I stupid!?! (Hannås, 2010, p. 116)

In other instances, however, the participants had managed to put together some of what it was that others were reacting to. Not uncommonly, this tends to be about the participants, in various contexts, behaving too actively, engaged or energetically compared with general norms of social interaction. This was expressed in different ways, but often, as exemplified by Sina's (34) story below, there was some sort of observable physical activity. In this excerpt, Sina casts light on a childhood memory, introduced by a little story about her own daughter:

*Sina (34):* My youngest daughter is *very* active. . . . And it hurts me so damn much when people comment: “Can't you get her to shut up? Can't you make her sit still? Man, that girl of yours is active!” . . . Because I remember those comments from when I was little. Like when mom and they were in the kitchen smoking when they had guests: “Are you kidding me, you haven't had that girl of yours checked yet!” And then I wondered if I was actually a mongoloid—and they hadn't told me. Because I was definitely different! (Hannås, 2010, p. 116)

The narratives in this category are often about the participants finally wondering whether their brain is not working the way it should. This interpretation can be said to be strangely consistent with the medical assumption that ADHD is caused by a neurobiological failure in brain function. The medical explanation for ADHD thus turned out to represent a reasonable rationale in the self-understanding for some of the participants. Mariann (33), for example, began our conversation with some reflections on the following memory:

*Mariann (33):* When I was about 12-13 years old, I was going around thinking I had a brain injury, but that no one dared tell me. I probably felt that something was not quite right, but I didn't understand what was wrong. (Hannås, 2010, p. 112)

After a long conversation, she finished her story by telling me about her own reaction when she was diagnosed:

*Mariann (33):* It was a relief to get it. . . . 'Cause I got . . . uh, like . . . this feeling that I had a brain injury—that they wouldn't tell me about—I *had* it! . . . In a way. . . . The fact that I was going

around feeling different and . . . that things were . . . were odd. Like, . . . I felt a little bit good about finally knowing that there actually *was* a reason. It wasn't because I uh—[pretended]. Like: I *was* different! And it was a good feeling [to get this confirmed]. (Hannås, 2010, p. 114)

Along with the narratives above referring to descriptions of concrete suspicions of disorders and brain impairment, there are other examples of less specific descriptions and more direct statements, such as this,

*Nora (33):* . . . since I was really young, I've felt that [*drawing a deep breath*]: I'm *not* like them! I'm not like *the others*! I'm not! (Hannås, 2010, p. 118)

### Identification

The background narratives about identification deal with how the participants at some point themselves identified their challenges with the ADHD diagnosis. This event turned out to have taken place at very different times in the various life stories. All of the 19 life stories contain narratives with this main theme. An eye-catching feature about these is that, generally, the participants themselves were the ones who asked to be referred for assessment. Only in 3 of the cases it was a worker in the specialist health service who first suggested ADHD assessment. For most participants, then, the process of identification with the diagnosis in other words started well before—and completely independently of—the diagnostic assessment of the individuals.

From the narratives about health-related disorders and problems, it was evident that most participants contacted their regular general practitioners (GPs) because of various types of somatic or psychological symptoms or complaints. The fact is that several participants were actually diagnosed with and treated for various other disorders before ADHD was ever suspected. In many cases, the follow-up of their own children, already in the process of being diagnosed with or treated for ADHD, seems to have had a crucial role in a process where the parents eventually related their own problems to their children's diagnosis. For example, Hanna (40), who had a son diagnosed with ADHD 2 years prior to our first encounter, supplied the following background for her asking for ADHD assessment for herself:

*Hanna (40):* When [*he got his diagnosis*] we enlisted him in the ADHD association, and received a lot of brochures and such. Among those was one about girls and women. I put that aside, because I thought that this has nothing to do with him! Heh! . . . And then I stumbled upon that brochure again later while cleaning. And I thought I would just have a *look* in it, before throwing it out. And then I had one of those—. “Wow, what is this,” I thought. “This is just so like me it's scary!” (Hannås, 2010, p. 117)

Instead of throwing the brochure out, Hanna put it aside. The next time she happened to come across it, she plucked

up her courage, and asked to be assessed for ADHD. All in all, 12 (eventually, 13) of the 19 participants in the study had children of their own. Some of the children were still babies; however, out of these 12, there were 7 participants who had at least one child with an ADHD diagnosis before they themselves were referred for assessment. In most cases, the parents identified with some descriptions of ADHD in women or adults, supplied by the specialist health care services. These descriptions were conveyed either by educational material or through courses following the assessment and treatment of their children. Linda (46) was one of these informants. She had several children with the ADHD diagnosis. She also had many years of various kinds of sick leave, assessments, and treatments behind her, before asking to be assessed for the same diagnosis as her children had. Linda aptly characterized the process these 7 participants had gone through: “I guess the way it works is . . . that I have inherited this diagnosis from my children, then?”

Even though several of the participants, for different reasons, had been familiar with the descriptions of clinical symptoms in diagnostic manuals for a long time, it was still not until they were acquainted with a kind of alternative description of the diagnosis that their suspicion of having ADHD themselves was raised.<sup>9</sup> Along with the official information that was disseminated through courses and brochures, alternative descriptions based on other people's personal experiences with ADHD had spread through the participants' social networks of family members, friends, and acquaintances. The participants' requests for assessment often seem to have been motivated by a sense of affiliation with “significant others.” The many examples of Linda's (46) narrative of “inheriting the diagnosis from her children” indicate that their own children often seem to perform as the “significant other.” There are also examples of siblings and other family members playing an important role in the identification process of the adult informants. In one case, the participant's own study work, and in another case, the mother's study work seems to be the trigger for the participants identifying with the diagnosis.

For the young people, it seems that friends are often the most important “significant others.” In the absence of problematic experiences, close relations with other young people with ADHD diagnoses appear to be a key factor in the process leading to formal assessment. An example of this is the following excerpt from Carl's (23) narrative:

*Carl (23):* A friend of mine—uh [who is] a bit older than me—went and got diagnosed with ADHD. And he, like me, reads a lot. He had read quite a lot about ADHD—and saw himself and also a lot of *me* in it, you know, as he read, . . . (I) sat down and started reading a bit—and I saw that it fitted. (Hannås, 2010, p. 122)

In the continuing process—that is, in the effort of obtaining a referral for an assessment by the specialist health care

services—the network of friends and family members with the diagnosis appears to be an important and useful tool. For example, Carl (23) told that he had simply “stopped by a therapist in a psychiatric youth team”:

*Carl (23):* I contacted him [the therapist] first. My friend, who was already getting treated there, had mentioned me to him. Because my friend and I are very much alike, in many ways. And he [the therapist] told me to just stop by, and we could have a chat. And after talking to him for a bit, he took me in for a proper assessment. (Hannås, 2010, p. 123)

As it turned out, many of those who had contacted their regular GPs because of their problems earlier, faced a kind of resistance when they asked to be assessed for ADHD. Not uncommonly, this resistance resulted in the participants having to go through a period of negotiation with their regular GPs before finally getting the referral they sought.<sup>10</sup> In cases where these negotiations appeared especially difficult, or even completely deadlocked, the participants solved their problem by bypassing their GPs. Like the participants who wanted an assessment without any previous health-related issues, they utilized the networks of their respective friends or family members to contact the specialist health care services directly. Rigmor (41), in this vein, told that she—after seeing one of her own children, one brother and several other family members diagnosed with ADHD—contacted her regular GP to get referred for ADHD assessment. About the following events, she told this,

*Rigmor (41):* I went to my GP. And then I asked for a referral for an assessment. And he started laughing at me. And he told me that “No, you don’t have [ADHD]” . . . He thought I was manic depressive, so he gave me happy pills. (Hannås, 2010, p. 121)

The GP explained to Rigmor, who was already on disability pension, that he regarded her chronic pain as a symptom of her depression. This, however, was a judgment Rigmor could not agree upon. As the GP had, practically speaking, denied her request to be referred, she tried an alternative approach to assessing whether or not she had ADHD:

*Rigmor (41):* So then, I rang the children and youth psychiatric service, and talked to the people I’m dealing with there because of my child. Because we have discussion groups, and we have—. I got an appointment there. . . . And then she did one of those—. And she said, “I can do a—, a straightforward, easy screening to see whether you have—, if you’re depressive.” Anyway, it was—, I think it was four or five sheets on one of those forms. Then she said, “You’re—, you’re nowhere near being depressive!” And NN [*name of therapist at the clinic*] did the same test then, before he started the ADHD assessment, to make sure I wasn’t depressive. (Hannås, 2010, p. 121)

In several narratives, the regular GP seems to have been reluctant to comply with the participants’ request for a referral, because, he had a different opinion of what the

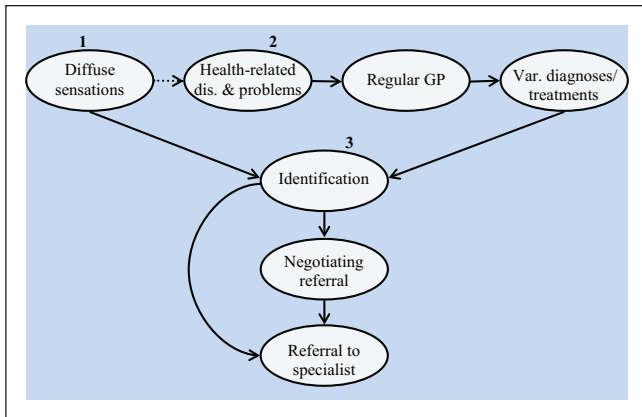
underlying cause of the problem might be. By directing the request directly to the specialist health care services, this kind of remonstrance seemed to be avoidable or possible to overcome.<sup>11</sup>

The participants’ narratives about identification also contain examples of reflection on why ADHD was not suspected at an earlier stage in their lives. The relevant explanations are closely tied to the question of how well their difficulties conformed to the various notions of the ADHD diagnosis at any given time. Many participants have experienced symptoms that could fit several diagnoses, and there seems to be a variation in terms of which diagnoses and which symptoms that have been most prominent at different times. In many cases, the participants’ problems have been perceived and described as something other than ADHD. The data material contains examples of the participants’ problems being treated as eating disorders, self-harm, depressions, bipolar disorder, allergies, learning disabilities, different types of social difficulties, and so on. Several of the participants grew up in a period when the diagnoses ADHD (or minimal brain dysfunction [MBD]) were frequently associated with aggressive, violent, or criminal (generally) boys, who were often referred to as “delinquents” or “hooligans.” Except from the youngest ones, a striking number of the participants pointed out that only children very different from themselves had been diagnosed with ADHD (or MBD) when they grew up. An example of this is Mariann’s (33) narrative:

*Mariann (33):* Um—we have, in our family, an extreme case of MBD. He got the diagnosis when he was 8, and he’s now 27. So he uh—he took all the attention for anything resembling MBD and ADHD. He was all over the place, and gets full score on every symptom—and heh! And so, all the focus—in the entire family—was on him. . . . “Uh—and my dad was in the MBD association. I think he was a member of the board. And my primary school teacher was also—, is on the advisory board for the ADHD association now. And *no one* had ever any idea that I could have anything like that!” (Hannås, 2010, p. 112)

Others, especially among the older participants, meant that they had always been considered as perfectly ordinary children. Some suggested that they from time to time—at the most—might have been seen as “troublesome” or “impossible” children. Instead of justifying their request for assessment by telling stories of diffuse sensations of being different, some of these participants, conversely, emphasized and explained which factors they believed might have contributed to them never experiencing any specific difficulties earlier in life. Peter (53) told about a good life, first as a child—both at home and at school—and then through years of working as an adult, before any difficulties emerged. He pointed out that he, for example, had never been aggressive while growing up. He also emphasized that he was both an only child, and belonged to a generation growing up with housewife-mothers, in a period of “proper conditions” and stricter demands on discipline at school. Carl (23), who





**Figure 1.** Key events and courses in youths' and adults' stories.  
Note. GP = general practitioner.

represents the next generation, believed that his teachers may have considered him a fidgety or distracted pupil. At the same time, he pointed out that this was a common phenomenon in the school, and not something that would raise any suspicion of ADHD. Carl (23), also, added that his mother had facilitated things so well for him that his problems never became apparent at home. He guessed that this also contributed to “it not being discovered before he became that old.”

### Key Events and Courses in the Stories

In the model shown in Figure 1, different events and courses in the various life stories are illustrated. The model is based on identifying seven different *key events* that were recurrent in the participants' stories. A key event, in this respect, is an event that turns out to be especially significant for the understanding of the events, and the way they are connected; that is, the course of events in the respective background narratives.<sup>12</sup> In the model, the relevant key events are labeled “diffuse sensations,” “health-related disorders and problems,” “regular GP,” “various diagnoses/treatments,” “identification,” “negotiation referral,” and “referral to specialist.” The arrows between the boxes in the model illustrate typical courses of events in the different types of stories about the background for the youths and adults being referred for ADHD assessment. The stories have different courses of events. The numbers 1, 2, and 3 (by each oval) refers to the starting point for the different stories, whereas the arrows between the ovals indicate what direction the course of events in the various narratives took.

In the first variety, the stories start out with narratives of different sensations of something being wrong. The next key event in these histories, “identification,” represents the stories of how the participants ended up identifying with the ADHD condition. From this point, there are two separate courses. One, proceeding by the key event “negotiating referral,” represents the stories where the participants contacted the primary health care services. In most cases, this

led to their having to negotiate with their regular GP before their referral to a specialist finally came through. The other course illustrates the development of the stories where the participants bypassed negotiations with the primary health care services, and—sometimes through middle men—directed their request for ADHD assessment directly to (a representative of) the specialist health care services.

The second variety of the typical courses of events starts out at Step 2 of the model, with “health-related disorders and problems.” The stories continue with narratives of the participants turning to their GPs for help with their issues, starting off a period of time characterized by assessment and trying out different diagnoses and treatments. From there, the stories continue with narratives linked to the subsequent key event, “identification.” These often proved to be connected to other close acquaintances or family members of the participants receiving an ADHD diagnosis. Onward, the stories take one of the same two paths as the stories starting out with “diffuse sensations.”

In the third variety, the stories start out with narratives of the key event “identification,” at Step 3 of the model. From here, these stories also take one of the same alternate courses as the other two varieties; continuing on either through negotiations for referral in the primary health care services, or directly (alternatively through a middle man with some sort of personal connection) into the specialist health care services. These stories stand out from the two former varieties in the sense that they represent a type of stories that does not refer to previous experiences, neither of distressing health-related problems nor of diffuse sensations. The lack of health-related issues may partially explain these participants' inclination to bypass primary health care services, and instead direct their request for assessment directly to the specialist health care services. It should be emphasized, however, that there were only 2 out of 19 instances of this kind of story in the empirical data material altogether.

The purpose of the above-mentioned model is to sketch a sort of analytical representation of three different courses of histories that stood out in the data material. The dashed arrow in the model's top left corner illustrates that the different narratives may also be part of one and the same life story. A life story might start out with a narrative of a diffuse sensation, continue with a narrative of health-related disorders and problems, before moving on to a narrative about a sort of personal identification with ADHD. The objective, in this context, is not primarily to quantify the different key narratives, but rather to display the different courses of events that emerged, based on the analysis of the participants' life stories. Table 2, however, provides insight as to how the three different main themes are distributed over four different varieties of histories in the data material.

The column on the far left distinguishes four different courses of events in the life stories. In the three following columns, “X” indicates which main theme is represented in the different types of life histories. The row labeled “Type 1”



**Table 2.** Narratives With Different Main Themes in Different Types of Life Histories.

Course of story	Diffuse sensations	Health-related disorders and problems	Identification (alone)	Number of life stories
Type 1	X			2
Type 2		X		7 <sup>a</sup>
Type 3			X	2
Type 4	X	X		8
Total	10	15	2	19

<sup>a</sup>One of the seven participants referred to problematic and violent behavior. All the others refer to health-related disorders and problems.

shows that diffuse sensations was the main theme in 2 life stories where health-related disorders and problems did not come up as a main theme. The row labeled “Type 2” shows that health-related disorders and problems was the main theme of 7 life stories where diffuse sensations were not a main theme. “Type 3” shows 2 life stories with identification as a main theme, without any of the other main themes being represented. Identification, as previously mentioned, was a main theme in all of the 19 life stories. The row labeled “Type 4” shows that, in 8 of the life stories, both diffuse sensations and health-related disorders and problems were main themes. The numbers in the bottom row of the table shows that diffuse sensations was a main theme in 10 of the 19 life stories. It is also apparent that health-related disorders and problems was a main theme in 15 of the 19 life stories, in total (including one describing problems with violence).

### The Search for an Explanation

Seventeen of the 19 life stories contain narratives in which the actions of the participants can be interpreted as an expression of their search for an underlying explanation or reason for their challenges.

In the narratives of *health-related disorders and problems*, this is often expressed by a steadily seeking for medical help and advice. The problems are perceived as symptoms of various diagnoses, and the participants are receiving various treatments, before ending up with ADHD as the final explanation of their disorders. The narratives refer to problems that are usually widely accepted symptoms of some sort of illnesses or health-related disorders. The problems appear unquestionable; the challenge is finding their root cause.

In the narratives of *diffuse sensations* such references to obvious, visible signs and widely accepted symptoms of illness or health-related disorders are lacking. Instead, this vague feeling of not being like everyone else is reported. As a consequence of repeated experiences of failure and social rejection, the participants however feel that something must be wrong. For lack of better options, some start wondering if they are suffering from some sort of brain impairment. The

lack of obvious manifestations as well as reasonable explanations is a common characteristic of these narratives. Hence, the participants’ search for an explanation is primarily motivated by a need for confirmation that their problems are real—and that there is an underlying reason for their problems.

By the end of the interview survey, 17 out of the 19 participants had finished their ADHD assessments, and received their conclusions. Fifteen of these 17 had the diagnosis confirmed, while 2 had their ADHD suspicions disproved. All of the 15 that were given the diagnosis described this as a major relief. This is in accordance both with results from other studies on ADHD in adults (Fleischmann & Miller, 2013), and with theories in the field of medical sociology (Frank, 1995). Interestingly, however, the same applied to the 2 participants that did not receive the diagnosis. One of these had asked for an assessment to get rid of the diagnosis (Therese, 19). The other one (Ida, 42), however, had strong hopes of confirming her ADHD suspicions.<sup>13</sup> Ida (42) had two children, both of whom had already received the ADHD diagnosis, and she herself had struggled with comprehensive health-related issues all of her adult life. In the same way that those who had received the diagnoses, she also, after a period of contemplation and confusion, expressed that having her ADHD suspicions disproved had come as a relief.

### The Significant Others

All of the 19 life stories contain narratives describing how the participants ended up identifying with the ADHD diagnosis. In 2 of the 19 life stories, *identification* was the only one represented out of the three main themes identified in the study. The fact that the participants did not describe experiences with any kind of problems or difficulties, and seemed to have identified with ADHD solely because of their acquaintances with the diagnosis, clearly makes these two life stories stand out from the others. It is similarly quite interesting that several of the older participants felt they had not been perceived as different from other children while growing up.

In the narratives of identification, several factors that in different ways seem to have contributed to the individual processes finally leading to a referral for ADHD assessment, are described. Some of them are related to a kind of availability. The sort of availability in question, however, has nothing to do with the geographical distance to diagnostic competence. Several of the participants had to travel quite far, repeatedly, to complete their assessments. Still, no one brought up this issue during the interviews. The analysis rather showed that the availability of “significant others” seems to have had a decisive impact on the participants’ decision to request an assessment for themselves.

Among those who most frequently appear as significant others are own children, siblings or other close relatives, and—especially with the younger participants—close friends.

The knowledge possessed by the participants about ADHD from other contexts seldom led them to identify their own problems with the diagnosis, and ask for an assessment. Along with the significant others, the opportunity for a kind of informal or direct contact with the specialist health care services appears to make the diagnosis a more available one. Social networks and relations to others with the diagnosis stand out as important factors helping adults to seek and obtain assessment for ADHD.

The significance of having children of their own with the diagnosis and the significance of the adults' own ability and will to persist in finding the cause of their problems are also pointed out by other researchers (Fleischmann & Miller, 2013).

## Concluding Remarks

The key questions of this article deal with how the ADHD condition is manifested, and which factors, at different points in time, seem to have affected the course of the lives of the youths and adults prior to their referrals for ADHD assessment. The analysis shows that the youths' and adults' life stories are especially characterized by three themes: *health-related disorders and problems*; *diffuse sensations* that "something" is wrong with them; and by *identification* with the diagnosis. Health-related disorders and problems seem to cause comprehensive problems in the everyday lives for the individuals. Even if this appears to be the most dramatic theme, the individual life stories also contain narratives of the other main themes. The course of events in a life story that contains all of the three main topics typically starts out with narratives of a diffuse sensation that something is wrong. Next, there are narratives of health-related disorders and problems. Finally, there are narratives of identification with significant others' modified descriptions of the diagnosis. This identification motivates the youths and adults to seek and negotiate their referral for ADHD assessment. Furthermore, the study indicates that close, personal relations with others with the diagnosis may be of great significance for adults getting assessed for ADHD.

This study has some obvious limitations. First, the analytic work is conducted by the author alone. All of the participants have, however, been sent the results of the analysis, and no one has made any critical objections. Second, the study was conducted in a very limited sample, thus, the results are not readily generalizable to a larger population. Despite its limitations, the study does reveal some issues that could be considered pursued in professional practice, as well as some questions that could warrant further research. One such question is whether the ADHD diagnosis will remain the final explanation of the questions raised by the youths and adults, namely, "why they are the way that they are" or "why things turned out as they did."

Through the interviews, it became clear that several of the participants and many of their close acquaintances were

relatively familiar with the diagnosis long before anyone suspected that the participants' own issues could be related to ADHD. The knowledge they possessed was based on the descriptions from the diagnostic manuals. It did not comply well with the adults' experiences of their own problems. This may indicate a basic lack of knowledge in the general public about the manifestations and consequences of this condition in adults. In addition, several adult participants faced resistance when requesting ADHD assessment from their regular GPs. This may indicate a lack of competence on ADHD in adults, as well as a lack of possible common comorbid problems, in the primary health care services as well. This is another question that might warrant a closer examination. If this should turn out to be a widespread issue, increased efforts in raising the competence level in the primary health care services could be useful. If no such efforts are made, we may be at risk of a continuing under-diagnosing of adults with ADHD.

Only a minority of the participants (2 of 19) in this study got the diagnosis without experiencing any specific problems or difficulties beforehand. These were two of the younger participant in the sample, emphasizing themselves that the diagnosis has become very common, and that their friends had it, too. The study sample is rather small, and these two constitutes a small share of the sample (less than 1:10). Still, it might be of interest to investigate how common this phenomenon actually is. A relevant question in this context is how one might explain that youths can be diagnosed with ADHD without fulfilling the formal criteria of significant distress or interference with functioning. If this should turn out to be an established practice, the consequence may be an over-diagnosing of youths with ADHD. Perhaps Therese's (19) story, describing a request for assessment to disprove her ADHD diagnosis, could be interpreted as an example of this kind of over-diagnosing? A research question that could cover all of the above-mentioned questions is whether we are witnessing a diagnostic practice that may lead to an over-diagnosing of youths and an under-diagnosing of adults with ADHD.

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## Notes

1. Different sources alternate between quoting 1988 and 1987 as the year when "ADHD" (Attention Deficit/Hyperactivity Disorder) was introduced as a term for a specific diagnosis in *Diagnostic and Statistical Manual of Mental Disorders (DSM;* cf. Baughman & Hovey, 2006; Brante, 2006).

2. The largest number for users of ADHD medication in the age group 10 to 19 years (i.e., 15,180 of 29,433 users in total), according to the National Prescription-Based Medication Register. Calculations based on figures from this register yields an average growth in the total number of users of 147.82% between 2004 and 2010. The corresponding growth in the age group 10 to 19 years is 103.62%, whereas the average growth for the age groups over 19 years of age is 361.40%.
3. In his description of “the looping effect of classifying human beings,” Ian Hacking (2004), for example, points out that diagnoses and conditions not only confirm each other but also seem to mutually reinforce each other (p. 279).
4. For a more thorough description of the sample, and so on, see Hannås (2010).
5. The quote is retrieved from a paragraph that speaks of validity in relation to narrative analysis. In my interpretation of the author, the truthfulness requirement is as relevant both with respect to the informants’ narratives and to what may be called researchers’ narratives or meta-narratives, that is, my own interpretations, reconstructions or analyses, based on the narratives of the informants.
6. Compare, for example, *Grounded Theory* (Glaser & Strauss, 1967).
7. A more thorough description of Labov’s method is found, for example, in Riessman (1993) and Fleischmann and Miller (2013).
8. The table may be subject to some inaccuracies. The categories are defined and bounded, based on the terms the informants themselves utilized in relevant narratives from their own lives. It is primarily the terms and explanations of the informants, not the formal definitions of the corresponding administrative categories that form the basis for the categorization. Despite eventual inaccuracies that this may have caused, I believe the main features and tendencies that are uncovered in Table 1 cannot be characterized as misleading.
9. In the network theory of Bruno Latour, which among other things describes how the knowledge of any given phenomenon is confirmed and spread through a network of diverse actors (“agents”), such descriptions are described as different “translations” of the phenomenon under study (Latour, 1987).
10. In studies of chronic illnesses, a phenomenon called “medical merry-go-round” is described. This term is related to a type of activity connected to patients’ and next of kin’s search for the maximum amount of information possible with regard to their own illness and treatment. After hours of dedicated information gathering through every available channel, the patients appear to be experts on their own condition, able to negotiate specific details with their doctors, both with regard to their own illness, and relevant forms of treatment. Bury (1997) describes this phenomenon in connection with the very outbreak of the illness, especially related to the activity that takes place after the diagnosis is given, and the treatment commenced. Furthermore, he claims that the activity decreases, and the patients and next of kin usually calm down after a certain amount of time. In terms of ADHD in youths and adults, however, the “medical merry-go-round” seems an appropriate description of a process that takes place prior to the diagnostic assessment for ADHD. The informants in this study, by all accounts, could not settle down, neither with the diagnoses nor with the treatment options they were prescribed before being assessed for ADHD. This led to new rounds of sick leaves, assessments, diagnoses, and treatments (cf. “medical merry-go-round”) before finally being assessed for ADHD.
11. According to Latour’s network theory, the specialists in this respect appear to be more effective agents than the general practitioners (GPs) in the primary health care services with regard to recruiting new members to the ADHD category. The network of agents for the diagnosis is growing as a consequence of more members being recruited to the category. However, Latour points out another, unavoidable effect of the same process. This shows that every new—and unique—case of a phenomenon identified, simultaneously implies a modification of the phenomenon itself. Each new group of members included in the ADHD category contributes to a need for change in the category itself. Correspondingly, the knowledge of the category must be subject to change—or “translation”—so that it at any point includes every new and unique variety of the phenomenon (cf., for example, the information brochures from the specialist health care services; Latour, 1987).
12. Riessman employs the term *key aspect* when describing both Labov’s and Gee’s models of narrative analysis. She states that, in both models, the analysis implies a “reduction to the core narrative” by using a “selection of key aspects.” “Key aspects” are, practically speaking, excerpts from the interview transcripts that represent specific functions in a narrative (Riessman, 1993, p. 60).
13. Ida (42) was one of the informants who were interviewed both before and after the assessment. In this context, it is interesting that she, unlike some of the informants who received the diagnosis, did not go on sick leave after the assessment.

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