Essay:

Beyond the other's world: An essay about the experience of social work with a diagnosis of Asperger syndrome

by

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Abstract

The essay presents a reflection on being a foreign and inexperienced social worker within a Norwegian social work context. I discuss challenges I have met in my work with when Asperger syndrome is diagnosed and reflect on power relations and the issue of self-determination within the field, in addition to analysing some critical incidents that made me rethink and reconstruct all of my experiences. I view my story from different angles and find different perspectives that show various ways of perceiving one thing. I discover the dangerousness of thinking in "black and white" and placing things in exclusive extremes, and lastly, I understand that I need to learn to solve problems by changing attitudes towards them.

Introduction

The following essay is a work that attempts to analyse my first experience within the field of social work, with the central topic of the essay being one of a reflection upon the experience of working with a person with Asperger syndrome. My story began when I started to work part-time as a foreign student in a social care institution in Norway, a position called an "environmental social worker" (or "miljøarbeider" in Norwegian). The general idea behind the profession lies in an interaction between the environment and individual in order to improve the individual's life quality (Halvorsen, 2006). In real practice, this involves helping people with disabilities in their everyday life with tasks such as shopping, cleaning, making food, walking and other social duties that would make them feel that they are living a "full life". Erving Goffman (1985) and Michel Foucault (1973) pointed out that the initial function for all institutions was to hide people with social, personal or behavioural problems from other people. However, the idea behind the profession changed one of making sure that people would not escape to helping people to adapt to society (Halvorsen, 2006).

I was born and grew up in Russia, a country where people with disabilities are still living separated from society; these people evoke pity and sympathy, but are not regarded as equal participants (Lokshina, 2012). Today, Norway's attitude towards people with disabilities is a result of a long-term period of changing and reforming. One of the most recent profound reforms in relation to the well-being of people with

disabilities took place in the early 1990s, when the most important aim of the reform was that people with disabilities would get as good as possible of an opportunity to live independent, meaningful and active lives on an equal basis with other people in society (Halvorsen, 2007). Most people with disabilities were provided with private housing, with medical and social personnel taking care of them.

The institution where I worked surprised me with its pleasant atmosphere, though I was even more surprised when I understood that there is no particular theory that the institution is guided by. "In practice, it does not always function like you want it to and as you learned it," one colleague told me. These words reminded me of an excerpt from Karen Healy's book (2005, xii): "The difficulties social workers experience in fitting 'square pegs' of their deeply contextual practice into the 'round holes' of social work theories leads to a view that theory is something done in universities, and that has little application in the everyday world of practice." Halvorsen (2006) explains the problem in the way that different theories give different types of advice, thus resulting in a disagreement about how and which theories could be used in practice.

I felt challenged without having some contextual starting point or theoretical support. Was it bad or good, positive or negative? Foucault once said, there is nothing that can be inherently "good" or "bad", but everything is dangerous (1984). The dangerousness of my experience implied the fact that I felt myself not enough familiar, both with the Norwegian context within social work practice and within work with people with disabilities. But at the same time, I was open to everything new and ready to reflect upon the new events that could happen in my work experience.

The following part of the essay will describe some moments of my experience that will be further discussed in this essay. I would like to make the reader aware that all the names and places are changed in order to protect the confidentiality of the people involved in the narration. I invite you to reflect on my experience and make your own conclusions, agree or disagree with me, and be an active and partial reader.

The first meeting with Asperger Syndrome

It was my first day at work when I noticed a tiny girl who attracted my attention with her unusual way of talking. She was really excited when one colleague said I was from Russia. She came so close to me that I could see her face in detail, and asked with the timid smile on her lips: "Are you really from Russia, from that big-big Russia?" "Yes, I am", I answered. "Cool! You know, I'm not from Norway either! I'm from Germany", she almost yelled.

This warm greeting made me curious and willing to know more about this girl, whose name was Amelia. I was told that Amelia could master almost all the daily routines on her own. Working with her, I should avoid some undesirable topics in communication, motivate her to make some food and go for a walk if she wanted to do that. These work tasks sounded pleasant and interesting to me, but I knew nothing about Amelia's illness, Asperger syndrome. I had never heard about this syndrome in Russia.

So what is Asperger Syndrome? Before I tell what happened between me and Amelia, I will briefly present some necessary information. Baskin (2006) defines Asperger syndrome (AS) as an autism spectrum disorder, which is characterized by difficulties in social interaction, repetitive patterns of behaviour and a focus on special objects or interests. AS became a standardized diagnosis in 1992 (ibid.). The brain of AS-diagnosed patients functions in a different way, and these people can often have difficulties with non-verbal communication, e.g. reading gestures and facial expressions. The misreading of the social and emotional aspects of a situation, sophisticated and verbal language, literally understanding words and jokes, the problematic use of one's own voice and difficulties with changing routines can all describe general AS symptoms (Baskin, 2006).The cause of the syndrome is unknown, and all the intervention techniques are aimed at diminishing the negative effects of the symptoms for a person and improving general function (ibid.). Attwood (1999) points out that every person with AS can develop their own strategies to learn and acquire specific skills and develop coping mechanisms. Some of these people can be passive and camouflage their clinical experience, while others can participate

actively in social relations and seek contact with others in spite of the possible negativity they can experience (ibid.).

Yet, when I met Amelia for the second time, I still did not know so much about Asperger syndrome. Bad? – No. Irresponsible? – Maybe. Dangerous? – Yes. I do not consider it to be bad because this allowed me to be unprejudiced and open, as I was not guided by characteristics such as "difficulties in communication" or "living in their own world". It was important for me to see the person first, to see her peculiarities, thoughts and actions. For me, the person is more important to me than their diagnosis.

It was a Saturday evening in early November, and Amelia came out to a common area when dinner was served. This time she looked different: the welcoming smile had faded away, and her face looked serious and worried. It was difficult to recognize the girl I had met a week before. During the rapport building time, it was said that there had been a conflict between Amelia and a care worker the day before due to a "misunderstanding". Amelia cried, and was really frustrated and angry, but she was better in the morning.

Amelia came to me and asked: "Who are you?" "Don't you remember me, the Russian women you met last week?" I asked. "Who is working with me today?" was her next question. "It's me", I answered. "Why?" Amelia said. I could not find an answer to this question. And she continued: "I don't know you, how can I be with you?" "But we can try and then we'll know something about each other". I said. "You **make me** get familiar with you?"…, she asked, and then continued, "I don't really want to know so many people around me. It's coming new and new and going away really soon, why should I be familiar with the entire town or maybe the entire world?" I was lost for a minute, and a colleague came to help. Nina, an experienced social worker said to Amelia: "But **it's not you or me**, it's not anybody here in this room who decides who will work with you. The leader, Anna, she decides! And you need to talk with her about it."

"Maybe you want some food, the dinner is served…" – I broke the silence… This was my first experience working with Amelia, as well as my first day at work.

The next time I worked with Amelia was the time before Christmas. Some Christmas music and baking made me feel relaxed and rested, though I realized that this calm could be the calm before the storm. Amelia came out and I asked if she wanted to make some Christmas decorations with me. She thought this could be a great idea, and we began our workshop. Normally, she would go for a walk around this time, so I also asked if she wanted to take a walk. She said that she really did not know, and I then reminded that it could soon be too late if she wanted to buy something or to go to a café. The colleague who was responsible for the shift happened to come into the room. He heard our conversation, and said that it was too dark, cold and windy to go out. "You shouldn't talk about going for a walk at all", Amelie said to me and continued, "Why can't I do things when I want and go for a walk when I want?" It became silent in the common area. "I *feel like I can't decide about myself* and everybody else makes decisions for me!" "Who makes you feel that?" asked the colleague. "Her!" Amelia said, pointing to me. I was kind of shocked by her words. The colleague just smiled and tried to make a joke about it. Situations like that were usually called "misunderstandings" and are not really discussed in the daily context of the institution, because it is believed they are often caused by the nature of the diagnosis of Asperger syndrome.

All throughout the evening, Amelia could not stop thinking about the situation she was living in. She said to me: "You know how many times I *feel myself to be powerless*. You can decide about yourself, but I can't. You are powerful, but I am not." What could I say to her about such a delicate topic? In this situation, I was afraid that all the words would be wrong, or that she might understand them in the wrong way. "It's all because I'm not normal, only *abnormal* people live here. I'm one of them", she continued. Nobody wanted to join the conversation, and I thought I knew why… It was not the first time Amelia discussed "the normality". I heard that other colleagues sometimes tried to make a joke to release the tension by saying that "all people are abnormal", though I did not feel like I could joke about this.

Why critical reflection?

What happened that day has come to my mind from time to time. I perceived it as a turning point in my understanding of the phenomenon of living with so-called "light syndrome". This also caused me to think what about what it can tell me as a social worker when the person you work with is aware of her diagnosis and has a capacity to reflect on it. In the following part of the essay, I will use the critical reflection technique developed by Jan Fook (2002) to revisit my experience in a conversation with the theories that I have learned in my social work education. According to Jan Fook (2002:39), the critical reflection approach can "assist us in subjecting our practice to a more critical gaze, at the same time allowing us to integrate our theory and practice in creative and complex ways". From a postmodern point of view, experience can be seen as a story or "text" where we can see the speaker's perspective on what took place and reflectively analyze to understand it in different ways that can help to challenge power relations (Fook, 2002). To help achieve a constructive and fruitful critical reflection, some techniques can be applied. One of them is the critical incident technique, which is described by Fook as follows: A practitioner needs to choose an incident from practice that was significant for a person for whatever reason and undertake a discourse analysis. Using these critical incidents as a part of the critical reflection process and responding on reflective questions, a person is involved in a process of "deconstruction" of the situation by reflecting upon it (ibid.). Furthermore, Fook advises us to develop questions that focus on one's own actions and ways of thinking, and which can help to reflect on the situation when we need to observe the main themes, terms, labels, categorization, perspective and explanation, the speaker applies and tries to interpret the situation differently using as many perspectives as possible. A practitioner can reflect on where knowledge, value systems, power or gender theory assumptions originate and what roles they support, in addition to which holes and biases the story has, and whether somebody or the practitioner himself supports these biases (ibid.).

To help reflect upon my practice and develop some practical knowledge, I ask myself questions such as: "What kind of theories can help understand the situation I described?" or "How can different theories enable me to catch different things, or how can I "re-label" categories for reconstructing the experience?" The story I presented

is such a critical incident, in which I hesitated, I got lost and I was uncertain as to how to react. How did this happen? How could I react "more professionally"? Or in the first place, what made Amelia think about her powerlessness? I take the last question as a point of departure to start my journey of deconstructing and reconstructing the experience.

Self-determination:"You can decide by yourself, but I can't"
Sarah Banks (2006:33) points out that ideas of Kantian philosophy have influenced general principles that determine the social worker-service user relationship, in which the key line is respect for an individual person as a self-determining being. The other important principle is the right of service users to "freedom and making their own decisions". My first working day with Amelia made me think if the principle was really respected in practice or not.

When she was wondering who she was going to spend her time with for that day, she answered, "It's not we or not you who can decide." And as I noticed when the question of power arises, in relation to this practice of pointing to the person who actually decides as if wielding a "magic wand" in situations like this: All the discussion becomes like a burned out candle. Now I think about other possible variations of the situation. If a person could never (even on weekends) choose whom she/he would like to spend time with, I think this would bring a strong feeling of dissatisfaction with life and the opportunity to make one's own choices and decisions. Now think about Amelia. Does she really feel that she is living a complete life? What if Amelia could get the right to choose who would work with her, who she would like to spend the time with, who she would like to talk with throughout the day out and go with for a walk or to see a movie? Wouldn't that be right?

I think about the report time when all the social/care workers get together to inform the next shift what has happened for this day and what should be done for the rest of the day. What if the users could have the possibility to get together and discuss the same things about us, the social or care workers? What would happen if the service users could participate in meetings like that and decide, change, prefer and choose the social workers they would work with?

As a matter of fact, I did observe such a "meeting", when Amelia and another service user discussed all the staff working here, agreed and disagreed, found different points, and pros and cons. They really respected each other in the conversation, but at the same they kept their opinion to themselves. I thought they might forget that I was there, but at the end Amelia said to me: "You should not discuss this with others, it's between us three." At this moment, I forgot the professional border between service deliverer and the service user, as they relied on me and revealed their thoughts. It was different from all the conversations I heard in the common area. It was a precious experience for me, and I never discussed this information with other colleagues.

This experience made me much more convinced that there is a huge potential to develop a possibility for self-determination. There have been many positive discussions about this idea, and I see that it works not only in theory. Even so, there is a lot of room to develop and refine this practice.

Karen Healy sees the disability services as "sites of a contest between social responsibility and self-realization (Healy, 2005:200). As a social worker, I have the responsibility to represent the interests and perspectives of the people, but as a representative of a "state-mediated" profession. I am also to use state control and power over individuals, so the conflict between the promotion of the user's welfare and the right to make my own choices can appear (Banks, 2006).

From my perspective, this type of "weekend self-governing" by service users could make Amelia a little bit happier and more confident. At the same time, the principle of self-determination and respect for the individual would be more "tangible" and noticeable in practice. But another question is: Can these ideas be real and be implemented into the context of a modern institution? Can I come with such suggestions without being ridiculed? That is the question of the next chapter.

It is all about power
If this alternative story can become true, the power relations between the actors can be profoundly influenced. As Fook (2002) considers, professionals lose power if

alternative perspectives are accepted, which can cause scepticism about the system or the "key frame of reference" (Healy, 2005: 194).

What is power and how do I perceive it in my story? How did my knowledge influence my assumptions and perception of the situation? All the formal academic knowledge I acquired in the previous years of education seemed to be highly grounded, but at the same time the contradiction among the classical theories, such as Marxism, structuralism and positivism made me feel that nothing could remain unquestioned. After becoming familiar with the postmodern perspective on relations between knowledge, theory and power, I understand that this position could explain my dissatisfaction with all the diversity of different theories. The other thing I must admit is that I have never thought about the constructive and transforming ability of power before I read about Foucault's work (1980). The perception of power that I "inherited" from my common sense knowledge in Russia is determined by its controlling and restrictive function. Those who possess power are often those who intimidate, and impose some actions without any deep reflective thought previous to action, and this authoritarian view of power control can be applied to all of the different fields of hierarchic relations. All of these things I had in my mental/psychological baggage when travelling from Russia to Norway.

The perception of "different power" and the realization of its more complicated nature came with the postmodern perspective in my life. As Foucault stressed in his work (1980), various institutions' (school, prison, hospital) claim "to help" and to "empower" can also be associated with the "will to have power" over others. Thus, by making people conscious about their "oppression", we impose our perspective and beliefs about the nature of their experience (Healy, 2005).

Through the postmodern lens, power is seen not just as control, but more as an "ever-present and productive feature of social relations" (ibid: 202). Foucault (1980) recognizes the productivity of power, and shifts the focus from paying attention to those who possesses power to how power is exercised. This point acknowledges the possibility of different groups of people, including people with disabilities, to exercise power (Healy, 2005).

As Jan Fook stated (2002), every person has the potential to create some form of power. As I can see from the behavior of Amelia through the Foucauldian perspective of power, she did exercise power when people could not discuss certain topics with her in the common area. She did so by complaining and provoking, thus silencing the professionals. Here, it is difficult to define who actually exercises more power, the "professionals" or the "service user".

How can I see and interpret the situation of my first work day differently? By questioning who should work with her, Amelia blamed the personnel and even the entire system in restricting her possibility for self-determination. The second incident reveals a different picture, but with the same main themes presented. Here, Amelia had a discussion on a binary opposition, powerless-powerful, though she also blamed me for deciding for her. Obviously, I was placed in a "powerful" position by Amelia. However, from my perspective, I see myself as a "victim" of her self-defending behavior since the direct restriction did not come from me, but from the colleague in charge that day. It was he who decided that the weather conditions were not good to go out for a walk. "The restrictor" could have another opinion about why Amelia and I should not have gone out at that time: I was inexperienced and not secure enough in my behavior to show that I could control the situation something critical happened, like Amelia acting out in a shop. Moreover, Amelia could also be afraid of a misunderstanding during the planned walk. Yet, she did not blame the actual restrictor, but instead blamed me as the "creator" of this uncomfortable situation. In addition, we can understand this blame because I was the contact person for Amelia that day.

As we see, this story can be seen and understood differently, and it could be difficult to find some "common" truths if we consider all the actor's perspectives. Here, I agree with Jan Fook (2002), who noted that there is no universal truth or reality, but instead that reality is constructed of multiple and diverse stories. The important aspect of postmodern thinking is to recognize the various ways of understanding theories, different types of practices and the multiple meanings of the practices (ibid.).

Furthermore, Amelia uses oppositional categories such as powerful/powerless in her argumentation, drawing a clear boundary between me and her as absolutely opposite parts. In this conversation, "our common world" was split into two, and she placed herself on the disadvantaged side. This positioning causes a disempowering effect on Amelia's well-being. Fook (2002) regards this kind of problem as being caused by the nature of this binary opposition, when one part possesses the power to "drag the blanket" to its side. At the same time, if we will change the position of the parts and make those "powerless" to possess and exercise power, we will automatically put the other group in a powerless position. In contrast, when Amelia expressed that she felt powerless, I did not recognize myself as the powerful part. To the contrary, I recognized myself to be in a vulnerable powerless position as well, an uncertain beginner in this practice field and a foreigner in a new Norwegian social work context. In this way, I notice a "transitional" position between the binary positions, which I think is not unusual in practice. This seems to have created a "power-neutral" relationship between me as a social worker and Amelia as a service user in that situation, when we were both put in the category of "powerless". But what I can see is that power is constantly moving and flowing between seemingly contradictory sides, thereby resulting in a transformation of power. When both Amelia and I can be placed in "powerless" and "powerful" positions at the same moment, we can consider power as an integrated holistic phenomenon.

The missing perspective

One of the contested key concepts in postmodern theory is a concept of "empowerment". It has different connotations, and can be understood as "power-sharing" or "as supporting and encouraging people to realize their own power and take actions for themselves" (Banks, 2006). The last definition is often linked to a radical approach that makes empowerment a part of anti-oppressive practices to work against structural oppression, and thus challenges a discriminatory system based on beliefs, politics, race, gender and disabilities. Amelia got a diagnosis of Asperger syndrome when she was a little girl. The word "diagnosis" originates from the Greek word "διαγιγνώσκει", which means "distinguish", "see a difference", "perceive" or "discern" (Oxford dictionaries online, 2012). The original meaning has a connection with the meaning of the word "discriminate", i.e. "differentiate" or

recognize the difference (ibid.). In other words, when putting a diagnosis on a person, we acknowledge that this person is different from others, and that this difference should be dealt with by applying some medical- or different therapeutic measures. All my work with Amelia should contain this "normalizing" process, and we expect to see her acting and behaving like a "normal" person in society. This diagnosis "label" is usually taken for granted due to the dominance of the biomedical discourse in society (Healy, 2005). The postmodern perspective emphasizes diversity in accepting that there are many different perspectives, and that those "unknown" and "secondary" perspectives can be valid (Fook, 2002). How can I understand Amelia's difference based on a postmodern perspective?

Willey (1999) and Clarke (2007) describe people with Asperger syndrome as being representative of a subculture. Those who agree and advocate this view insist on accepting that there is no perfect configuration of the brain or a perfect human behavior for human beings. They promote the standpoint that people should be tolerant to different variations in the human genome (Clarke & Amerom, 2007). These views have promoted movements for autistic people such as ARM (Autism Right Movements), whose aim is to create social networks and events, in which autistic people can socialize on their own terms. This movement is fighting for the recognition of autistic people as a minority group that does not need a cure, but rather the acceptance and tolerance of society (Solomon, 2008).

As researchers of Asperger syndrome, Clarke and Amerom (2007) support these ideas and point out that Aspergers syndrome can be viewed as "a different cognitive style", but not as a disorder or disability. It should not be treated as a diagnosis in the same way as homosexuality, which is not recognized as a disorder any more. Baron-Cohen (2002) discussed scientific contributions made by talented autistic people, as well as the possibility to exclude AS from the "official list of disabilities" in spite of arguments such as a lack of empathy and emotional difficulties.

Such an alternative understanding on autism and AS can be the "missing perspective" (Fook, 2002) in my story. It makes me think that the right movements for autistic people can achieve really great results in changing attitudes toward AS. I

believe that this idea can take root in the reality of the Norwegian system of social care, but it may take much time and effort. By now, some people with AS and their parents really want to have this understanding to become "mainstream" in the production of social care and welfare. It could be great to know what Amelia thinks about this different attitude to her "disorder". But do I dare to discuss such a topic with her? As Fook (2002) points out, simply choosing not to accept dominant ideas can contribute to challenging and changing the dominant systems. But do people like Amelia need this change or can these ideas be seen as being imposed from the outside, from an inexperienced social worker from another social and cultural context? There can be a great risk in talking about these ideas with Amelia, as it can make her feel more oppressed, which is the opposite of what I want to accomplish. Celebrating diversity: "Normal-not normal", "different" or just unique?

Amelia used another binary opposition, "normal-abnormal", to describe social workers and other people vs. service users in the institution. However, there is a great difference within the unified groups of "people with disabilities", as well among Amelia's normal "others". Using this unifying statement, "nobody is normal" often helps to save the situation and change negative and destructive thoughts, as Amelia usually agrees with this viewpoint. We put all the people in the category of "abnormal", presenting "normality" as something artificially constructed, perfect and therefore not really achieved. In a situation like that, the emphasis should be moved from opposition to something that can unify us. What all the people in the world possess in common is exactly that every person is unique. Diversity is not equal to "abnormality". The binary opposition actually contains in itself a million or even more different variations and possibilities. Societies can construct as many categories as possible, although the diversity in the categories will point towards the unique nature of all human beings. As Fook (2002:74) has said: "To define people simply in terms of structural categorization also seems to deny the rich variety of combinations, indeed individuality, which can arise from the variety of backgrounds, experiences and changes."

Amelia often discusses the me-you relationship, in which she opposes the world of professionals and service users, but sometimes she talks about things that we share

in common, such as the Norwegian language and our common "minority" position in the system. For example, when we met for the first time, she emphasized this common foreign background between us. Amelia likes to pay attention to our internationality and ask about my culture, my language and my traditions, while I like to ask about her German background and her perspective as a German immigrant. In these moments we reposition ourselves, and we rethink the stereotypes. We are proud of ourselves being a minority, and we are celebrating diversity. We both live in a different social context now than where we were raised, but we cannot remove all traces of our native culture, as elements of it will always appear spontaneously when we apply it (Burkitt, 2008).

My position as a foreigner within the system of social care in Norway can be said to be the whole and the bias of the story. I stand in opposition to the Norwegian staff, which makes my knowledge and experience less significant and appropriate, therefore admitting the dominant Norwegian perspective without challenging it. Putting the category of "minority" on me can have a disempowering effect in relation to all my "indigenous" knowledge, experience and education. As I can now see, this "minority" background can be an advantage when working with service users like Amelia.

Closing thoughts

Throughout this essay, I have discussed the critical issues caused by some incidents in my experience of social work with a girl with Asperger syndrome. These incidents made me think about different aspects of the social life of a "marginalized" person in society. In the end, I understood that I perceive my perspective as also being marginalized, and recognized the possible dangers of such thinking. I learned a lot through the application of a critical reflection approach to my stories and my attempt to reconstruct and redevelop it in a new vision of the situation. I began to recognize the different functions and opportunities of power, such as its productivity. I learned to not be afraid to be myself and express my own vision and perspective. At the same time, I began to realize the importance of balance and taking into consideration all the possible risks that my actions can bring, such as the "disempowering effects" in an attempt to empower the service users.

The important discovery for me was the "pitfalls" of dichotomous thinking that sometimes created irresolvable dilemmas by placing things on opposite and mutually exclusive extremes. I began to believe more in positive changes, but to me changing became about changing attitudes and seeing the problem through "different eyes and minds", hence applying different perspectives. And I do believe that this vision will absolutely contribute to my further practices and experiences as a social worker.

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