The effects of an Autism Spectrum Disorder Diagnosis on the identity concept

Breakwell's Identity Process Theory
investigated in interviews
following Mayring's Qualitative Content Analysis

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Abstract

This paper investigates the effects of an Autism Spectrum Disorder diagnosis on the identity concept of an individual. Identity is conceptualized according to Breakwell's *Identity Process Theory* (Breakwell & Jaspal, 2016). The research is conducted by two semi-structured interviews with diagnosed individuals and a following qualitative content analysis following Philipp Mayring (2014). The following findings are presented in the paper;

1. Accepting the ASD diagnosis as part of one's identity leads to insight, accepting oneself and increases self-efficacy and self-esteem.

2. Retaining a continuous sense of self across diagnosis enhances the ability to accept it.

3. Self-efficacy and self-esteem are negatively affected by social stigma around the category of ASD.

Furthermore, positive and negative conditions for these factors are discussed in the paper, as well as recommendations for further research and points of departure for treatment.

Aim of the paper

The aim of this thesis is to explore the research question within the theoretical framework of the Identity Process Theory (IPT) (Breakwell & Jaspal, 2016) by conducting semi-structured interviews and the following qualitative content analysis.
In specific, it will be investigated how a categorical diagnosis following the DSM-5 affects the self-concept of people with Autism Spectrum Disorder. To reach this aim, the categorical approach will be introduced in order to find the critical aspects of it possibly affecting the self-concept of a diagnosed person. The Identity Process Theory by Breakwell (Breakwell & Jaspal, 2016) will be introduced and used as the theoretical framework for deriving hypotheses about possible impacts of the ASD diagnosis on the self-concept.

Scientific relevance

Critical reflection on the categorical diagnostic approach to psychopathology

When reflecting on the effect of diagnostic classification on the identity concept of the patient, it is important to understand the main diagnostic tool used in the practice of clinical psychology. Currently the Diagnostic Statistical Manual - 5th version by the American Psychiatric Association - is the most commonly used methodological tool to identify and classify psychopathology (Davey, 2015, pp. 38).

The DSM-5 is a diagnostic classification system which defines disorders as discrete entities which are separated from each other and from normality (Davey, G. 2015, pp. 38) - the so called categorical approach to psychopathology. During the process of classifying a patient, discrete criteria (symptoms) are identified and depending on minimum requirements being fulfilled or not, the patient will either cross a classification threshold, or not, resulting in a binary outcome; being classified with Autism Spectrum Disorder, or not. This structure provided for diagnostic processes as well as the common language it provides for clinicians are of immense benefit for clinicians (Nathan, 1998, pp. 3-27). Moreover, the DSM-5 provides objective, observable behavioural symptoms to classify a disorder without making suppositions about the underlying causes (Davey, G. 2015, pp. 38). This allows different clinicians across settings to apply the criteria systematically in a unified manner, without theoretically favoring one approach to psychopathology over another. But this categorical approach also contains some disadvantages.

To begin with, treating disorders as discrete entities does not account for the high comorbidity rates between disorders, which are the rule rather than the exception within the group of mental health patients (Krueger & Piasecki, 2002). Distinctness of disorders within the categorical approach might therefore not be accurate and creates a reductionistic picture of mental conditions.

Distinctness of categories suggests that disorders are entities in themselves, which implies their existence and persistence across contexts and times and therefore attaches the characteristic of stability to them. This notion of stability of disorders is not only inexact but also makes them seem more difficult to overcome compared to physical illness for the individual in question and increases social stigma around those individuals suffering from a mental disorder (Khoury, Langer & Pagnini, 2014, pp. 3).

In reality though, normality in terms of mental well-being and psychopathology are part of one spectrum. The issue with a categorical approach to psychopathology is therefore not the diagnostic process according to the DSM-5, as a full diagnosis is much more nuanced and entails an in-depth exploration of the patient including individual specific details. The problem lies much more in the category which a diagnosed patient is assigned to, as this only displays a heavily reduced version of the diagnostic process. Moreover, the public is not aware of the detailed diagnostic process and the information gathered and discussed within that process. Oftentimes, the public only is confronted with the category as the ultimate product of the diagnostic process which leads to the misunderstanding that a disorder is an entity distinct from the normal distribution of mental health.

This misunderstanding can lead to public stigma, which is investigated as a possible influencing factor on one's identity concept and therefore introduced in the following paragraph.

The effects of Stigmatization

Generally, the majority of people in the United States and in many western European countries hold stigmatizing attitudes about mental illness (Corrigan & Watson, 2002). This is called *"public stigma" - "the negative reactions that the general population has to people with mental illness".*

Public stigma adversely affects children with Autism spectrum disorder across cultural contexts (World Health Organization, 2016). Content of public stigma against children with ASD often include being viewed as willfully disobedient and disruptive when displaying socially inappropriate behaviours in public (Gray, 1993; Ling, Mak & Cheng, 2010).

Furthermore, internalizing the public stigma can lead to *"self-stigma - the prejudice which people with mental illness turn against themselves"* (Corrigan & Watson, 2002) which in turn might lead to loss of self-esteem and self-efficacy (Corrigan, Watson & Barr, 2006) and prevent individuals from pursuing their life goals.

These previous lines of research and the highlighted findings point towards the conclusion that the assignment of a category as an endpoint of a nuanced diagnosis does not accurately capture the mental health conditions of patients. This can lead to social and self-stigma, which can lead to a loss of self-esteem and self-efficacy, which are associated with Major Depressive Disorder.

This thesis, however, does not seek to propose an alternative approach to the categorical diagnostic approach embodied by the DSM-5 but intends to explain the importance of a deeper understanding of the negative effects of a category on the individual. These negative effects on the individual seem to be caused partly by social stigma being internalized. To prevent negative effects for individuals to occur, the mechanisms leading from social- to self-stigma need to be investigated.

Relevance of Identity concept

I propose here that the mechanism from public stigmatization to self-stigmatization can in part be explained by understanding procedures of identity or self conceptualization. In order to investigate these mechanisms I will answer the following questions; what are comprehensive theories of self-identity? Self-identity is defined as the structure that we call our 'self', including information about us and judgements about this information. How does a categorical diagnosis according to the DSM-5 affect the self-identity concept according to the theoretical framework?

I will investigate these questions in the specific case of autism spectrum disorder (American Psychiatric Association, 2013, 299.00). Research for other mental disorders concluded for example regarding PTSD sufferers, that perceived loss of psychological autonomy, accompanied by the sense of not being human anymore, challenges the individual's sense of worthiness and competence and is positively associated with the severity of PTSD (Ehlers & Clark, 2000). This phenomenon is termed *'mental defeat'* in the described paper and provides support for the hypothesis that perceived aspects of mental illness contribute to one's concept of self.

Furthermore, a study about perceived stigma in persons with a diagnosis of bipolar affective disorder concluded that concerns about stigma associated with the diagnosis predicted poorer social adjustment in a seven months follow-up evaluation (Sirey et. al, 2001). This study provides further support for the importance of identifying mechanisms by which social stigma can result in self-stigma and affect the identity concept negatively.

In the specific case of autism spectrum disorder, there are debates among scholars as well as diagnosed people and autism activists concerning the language that should be used to describe affected people (for a full review see Kenny et. al 2016). Two alternatives are the use of person-first language which refers to people first as an individual and then to their disability if necessary - person with autism - in order to give prominence to the individual over their disorder. Opposed to that stands the disability-first language with the rationale of recognizing the experience of living with the disorder / disability. This paper highlights that categories play a significant role in one's concept of self, and the literature on Autism Spectrum Disorder is currently lacking a theory of the underlying mechanisms for this importance.

Literature review as theoretical framework

Changes in our environment and society require individuals to adapt to them and integrate the new information into their concept of self in order to adapt successfully. For example, Erikson's psychosocial developmental theory of identity describes the challenges of combining individual needs before young adulthood, such as independence and sexual expressiveness, one's physiological maturation and cognitive sophistication, with social demands (Marcia, 2001).

Receiving a diagnosis of any mental illness, but in specific of ASD, is an experience which needs to be incorporated into the identity concept. To support this claim, identity conceptualizations of Erik Erikson, and Glynis Breakwell will be reviewed, with the main focus being on Breakwell's Identity Process Theory (IPT) as informing the following interviews with young adults with an ASD diagnosis.

Erikson's psychosocial developmental theory

Erikson's psychosocial developmental theory is to be regarded within the context of a psychodynamic theory, identity being a developmental structural concept which is malleable across time. It is furthermore based on the principle that certain individuals' abilities will develop in predictable stage sequences if the individual is embedded within an 'average expectable environment' (Marcia, 2001). Erikson describes identity as an *"...unconscious striving for a continuity of personal character."* (Erikson, 1980, pp. 109). 4 stages need to be resolved positively during childhood, according to Erikson.

1. A sense of basic trust (from infancy), meaning developing a sense of the world and oneself as being trustworthy.
2. Autonomy (from early childhood), indicating the balancing of one's own demands with the demands posed on oneself by the significant social figures in one's life.
3. Initiative (from play age), in which autonomy is operationalized in order to plan and complete physical and interpersonal tasks.
4. Industry (from school age), describing the immediate precursor to identity by experiencing oneself as a competent part within the structure of school demands.

Due to "Persistent deficits in social communication and social interactions across multiple contexts" (American Psychiatric Association, 2013, 299.00 A.) as a diagnostic criterion of ASD, positive resolvement of stage 2-4 as defined by Erikson is expected to be more difficult for affected individuals. Therefore, developmental issues as part of the nature of ASD can be understood in terms of psychosocial theories and in order to manage these issues, threats to identity development in people with ASD need to be better understood. In order to further elaborate on these threats to the development of an identity concept, posed by being diagnosed with ASD, I review Glynis Breakwell's Identity Process Theory. The effect of an Autism Spectrum Disorder diagnosis on the identity concept is theorized within this framework. This specific theory is chosen as the theoretical framework because it explicitly focuses on threats to identity, therefore being a useful theoretical tool to identify issues with development of an identity and their possible solutions. It is preferred for the purpose of the study due to the emphasis on processes as compared to the stage-wise outcome focussed theory of Erikson.

Breakwell's Identity Process Theory

Breakwell (Breakwell & Jaspal, 2016, pp. 20-38) developed the *Identity Process Theory (IPT)* in order to explain how people incorporate every aspect of one's life (e.g. social categories, experiences, relationships, activities, preferences etc.) into one's concept of self-identity. The core assumption of the theory holds that people have the desire to construct and maintain a sense of identity throughout their lives, recognizing that this identity is a complex and dynamic phenomenon. Especially interesting for this paper, is that identity in this theory is neither fully socially nor fully individually constructed. Individual aspects of one's identity are internal values, attitudes, temperament, cognitive styles and so forth, whereas aspects of a social identity encompass group memberships, relationships, social categories, etc. According to Breakwell, social and individual identity are not two sides of dichotomy, but influence each other, as social constraints on the identity are reactions to individual attitudes, and social components of one's identity become part of the personal identity. Therefore, a dynamic interplay between the historically separated components of identity emerges which makes it impossible and unnecessary to separate them.

Instead, Breakwell distinguishes between two different components of identity; (1) *Content* and (2) *Value / Affect* and two universal processes guiding these dimensions; (1) *assimilation-accommodation* and (2) *evaluation*. The content dimension literally refers to the content of one's identity; which information it entails and is guided by the principle of assimilation-accommodation. This process refers to the presentation of additional information relevant to one's identity, integrating it into the self-concept, and the following adjustments made by the person in terms of actions. Evaluation steers the value / affect dimension, giving meaning and assigning positive, neutral, negative or mixed (= context specific) value to the content of one's identity.

Originally, Breakwell identified four underlying motivational principles which define these two universal processes.

(1) Continuity - concerning the need for a consistent sense of self across time and situation

(2) Distinctiveness - meaning the desire to be unique as an individual and different from others.

(3) Self-efficacy - referring to the feeling of being confidently in control of oneself and one's life.

(4) Self-esteem - describing the feeling of an intrinsic personal sense of worth.

Furthermore, coping strategies are an important part in Breakwell's theory. He described coping strategies as "any activity, in thought or deed which has as its goal the removal or modification of a threat to identity". A threat to one's identity occurs when one of the two universal processes (assimilation-accommodation or evaluation) does not combine successfully with the motivational principles of identity.

Research questions and hypotheses

Research questions

I will analyse the effects of receiving a classification of autism spectrum disorder within this identity framework. That is to answer the questions of;

> a) Which place does the diagnosis take within the structure of one's identity and specifically; which place should it take within the self to cope with the diagnosis positively?
>
> b) In what way does the diagnosis pose a threat to identity, according to the definition by Breakwell of the diagnosis conflicting with motivational principles?
>
> c) How is social stigma incorporated into the concept of identity, leading to the negative outcome of self-stigmatization?

Attending the first question (a), there is research showing the importance of integrating one's own autism into the self-concept by accepting it as a part of the identity structure. To begin with, concerns about developing a self-identity are common among adolescents with autism (Cage, Bird & Pellicano, 2016) but doing so is an important factor of mental health (Meeus et al, 2012). These general findings are supported for autism spectrum disorder by research displaying that failing to accept one's autism is a predictor of depression (Cage et. al, 2018) whereas accepting one's autism reduces the chances of depression and anxiety significantly (Cooper et. al, 2017). Therefore, it proves that the diagnosis of ASD needs to be incorporated into one's identity, by being accepted, to result in a positive outcome. Suggestions for processes contributing to the achievement of this goal are given in the following paragraphs, as answers to questions (b) and (c).

Included in the severity criteria of ASD in the DSM-5 (American Psychiatric Association, 2013, 299.00) is the *"Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour"* which is specified with the examples of *extreme distress at small changes, difficulties with transitions, and rigid thinking patterns (among others).* These cognitive aspects of the disorder already point towards new information about one's own identity as especially threatening and inherently difficult to cope with.

Therefore, in the context of Breakwell's identity process theory, a diagnosis of ASD is hypothesized to potentially influence 3 of the motivational principles in a negative way. The

notion of continuity of one's identity across time and situation could be threatened by an ASD diagnosis in the case of the individual not having recognized the diagnostic details (behavioural, cognitive, emotional patterns) themselves before being presented with them in the diagnostic process. This would disrupt their previous perception of themselves.
Following, it seems the more awareness there is of described diagnostic details before the formal diagnosis, the lower the threat posed on the principle of continuity will be. This is given that a person has a sense of themselves as being different from others, and displaying behaviours meeting those of the ASD diagnostic criteria, before being diagnosed.

The motivational principle of self-efficacy was influenced by a preceding model of the concept of self-efficacy by Bandura (Breakwell & Jaspal, 2016, pp. 7). Bandura defined the term as *"the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations".* It is important to note that self-efficacy is distinct from self-esteem in Bandura's as well as Breakwell's theories. It does, compared to self-esteem, not refer to the actual success of oneself in managing situations but to the *perceived ability* to do so. Furthermore, it is not concerned with an intrinsic value of oneself (as it is in the case of self-esteem) but instead with one's perceived agency and control over one's actions.

Therefore, self-efficacy can be threatened in the case of an overly rigid presentation or perception of the category of autism spectrum disorder, referred to earlier as the notion of stability of a diagnostic category (see page 1). Additionally, ASD not being "curable" in the traditional sense of it not disappearing, can contribute to the notion of stability. A stable and rigid perception of the ASD diagnosis can lead to the autistic person losing the perception of control over their actions and losing the belief in one's abilities. But a diagnostic process includes much more person-specific detail than the reductionist category of autism spectrum disorder, and if those details are communicated from clinician to patient in an appropriate and non-rigid way alongside suggestions of coping mechanisms, the category itself would not feel rigid and reductionistic to the patient and therefore not affect self-efficacy negatively.

Breakwell draws attention to the identity concept being an ongoing psychologically as well as socially influenced process (Breakwell & Jaspal, 2016, p.5). He states the importance of social representations in determining the content of identity as well as the value assigned to its components. Consequently, if the society around an autistic person lacks a thorough understanding of their condition (a lack of psychoeducation) and holds stigmatizing (negative) attitudes towards the abilities of them, it can affect self-efficacy negatively.

Moreover, self-esteem could suffer when evaluating one's autism through the perception of stigmatizing others. Thus, a stigmatizing environment is expected to lead to a reduction in self-esteem and self-efficacy due to the social influence on the identity concept. On that account, a positive outcome is presumed given that the society around is well informed about the person-specific diagnosis of ASD and additionally evaluates the person as largely positive. This could be achieved by autistic people disclosing their autism to their environment and on a larger scale by appropriate psychoeducation concerning autism.

Hypotheses

In conclusion, the hypothesized threats of an ASD diagnosis on the identity and their possible solutions are threefold; concerning the motivational principles of continuity, self-efficacy and self-esteem.

1. Above all, the need for accepting autism as an aspect of one's identity is hypothesized to be the first step in order to develop a healthy way of coping with one's autism.

2. Secondly, continuity could be threatened in the case of the diagnostic details disrupting one's sense of identity. This means in turn, that awareness of the diagnostic details before being confronted with them is expected to prevent the diagnosed individual from this threat to identity.

3. Self-efficacy could be negatively affected by a reductionistic categorical perception of the diagnosed person by the social environment. Psychoeducation of the general public as well as detailed and clearly communicated diagnostic details and coping strategies by the practitioner are expected to alleviate this negative effect on self-efficacy.

4. The threat on self-esteem is theorized as similarly influenced by negative evaluation of the social environment, which influences the evaluation of oneself in a negative way. This effect could be overcome by psychoeducation to reduce social stigma and by active disclosure of the autistic individual about their diagnosis to their environment.

In order to test these theories about the processes of identity formation caused by a diagnosis of ASD and to identify the mechanisms by which it can be integrated into the self-concept, two qualitative interviews will be conducted with young autistic adults. The goal is to test the importance of the above aspects for dealing well with one's own autism and learning from the experiences of affected individuals.

Methodology

Research design

The investigative form of semi-structured interviews was chosen in order to directly target the hypothesized concepts and test them. Moreover, it leaves room for myself, the researcher, to inquire further detail about relevant topics and to change formulations from the protocol to keep a conversation flow. Two interviews were conducted. The first interview was conducted in collaboration with my supervisor (Kirstin Greaves-Lord), in which she took notes because participant 1 did not agree to be recorded. Therefore, the first interview was noted down as accurately as possible and transcribed into a clean and smooth verbatim transcript after the interview session to create a coherent text which still represents the original content. The second participant agreed to audio recording and therefore the spoken words were transcribed into a smooth verbatim transcript. In the second interview Kirsten Greaves-Lord asked questions as well, which are indicated in the transcript as ***K:***, whereas my questions are indicated by ***I:*** and the participants responses as *P:*. In the second interview the original structure of the interview was not abided by well, but the topics of the questions were still covered as indicated by stating the original interview questions above the interview section which they relate to. The two interviews took approximately 60 minutes each. Both of the participants signed an informed consent form before the interview. In order to protect the identity of the participants, the consent forms are not in the appendix, but can be requested for a review from Kirstin Greaves-Lord (k.greaves-lord@lentis.nl).

Sample

The sample consists of two male, autistic adults. Participant 1 was 30 and participant 2 25 years old at the point of the interview. Both their nationalities are Dutch and they are clients of the Autism Team North Netherlands (ATN - https://www.lentis.nl/locaties/atn-groningen/) in Groningen. ATN is a mental health institution which specializes in diagnosing and treating people with Autism Spectrum Disorder. The interviewees participated in a social skills training led by my supervisor Kirstin Greaves-Lord, in which they indicated their willingness to participate in the at this moment ongoing research study 'Omgaan met (het eigen) autisme' for which my interviews serve as a pilot study.

The participants meet inclusion criteria for this topic of investigation due to their ASD diagnosis and conducting interviews with them serves to gather experiences and valuable insights on the important concepts when investigating good ways in which to deal with one's autism. The sample is not representative, but to be regarded as individual accounts of the importance of concepts such as identity, continuity, self-esteem, self-efficacy and (internalized / public) stigma in dealing with an ASD diagnosis.

Construction of interview protocol

The interview protocols are composed to target the theory-based concepts of;

- **Identity** - including the motivational principles of continuity, self-esteem, self-efficacy (as formulated by Breakwell)
- **Public stigma** - as mediating the effect of an ASD diagnosis on motivational principles of identity
- **Internalized stigma** - as another mediator between the effect of an ASD diagnosis on the motivational principles of identity
- **Disclosure** - as reducing public and thereby internalized stigma
- **Psychoeducation** (of the public) - as reducing public and thereby internalized stigma

Because this thesis will serve to inform the overarching Project "Omgaan met (het eigen) Autisme" as a pilot study, and access to participants is limited for me, the interview protocol could only be tested in an unofficial setting with my supervisor. The questions were constructed in collaboration with Kirstin Greaves-Lord and Benjamin de Graaff (k.greaves-lord@lentis.nl, benjamin_degraaff@hotmail.com) .

Breakwell's Identity Process Theory has informed the hypotheses and interview questions in a deductive manner. Validated and reliable scales and research papers were used *(Figure 2.)* in order to construct the category system of the following Qualitative Content Analysis of the interviews, which will later be described in further detail.

Interview Question number	Target Concept	Validated scales / research papers	Concepts in scales / research papers
1	General overview of social environment		
2	Time of Diagnose		
3	Diagnostic process + information detail + autism identity		
4	Continuity of Identity	Breakwell & Jaspal, 2016	Continuity

			- A self consistent *"...across time and situation" (p. 4)*
5	Continuity + Acceptance of diagnose into identity	Breakwell & Jaspal, 2016	Continuity - A self consistent *"...across time and situation" (p. 4)*
6	Autism Identity	Cooper, Smith, Russell, 2017	Main findings: Accepting one's autism reduces the chances of depression and anxiety
7	Public stigma + correlation to being informed about autism	King et. al. 2007 Sasson & Morrison, 2017	Public Stigma - the social environment having a negative attitude towards the diagnosis - being discriminated against in work or educational opportunities and settings due to the diagnosis - being avoided or insulted due to the diagnosis.Main findings: Educating peers reduces social stigma First impressions of adults with ASD improves with diagnostic knowledge of peers
8	Internalized stigma and effects on - Self-efficacy - Self-esteem	Internalized Stigma of Mental Illness (ISMI) scale (Boyd,Adler,	Internalized Stigma - Social withdrawal - Alienation - Stereotype

		Otilingam, Peters, 2014) New General self-efficacy scale (NGSE) (Chen, Gully, Eden, 2001) Rosenberg self-esteem scale (Rosenberg, 1965)	endorsement Self-efficacy - Overcoming challenges - Goal-achievement - Task-success Self-esteem - Ability to complete useful tasks well - Self-worth / -respect / -pride - Self-satisfaction - Possessing good qualities
9	Disclosure leading to higher self-efficacy and self-esteem	Sasson & Morrison, 2017 Ritsher, Otilingam, Grajales, 2003	1. Disclosure -> reduction of public stigma 2. Public stigma -> internalized stigma -> eroding individuals social standing, diminishes self-esteem and recovery
10	Public stigma reduction by disclosure / psychoeducation	Sasson, & Morrison, 2017	1. Educating peers reduces social stigma 2. First impressions of adults with ASD improve with understanding of peers
11	Challenges Self-efficacy, Self-esteem	New general self-efficacy scale (NGSE) Chen, Gully, Eden, 2001 Rosenberg	NGSE - overcoming challenges - Goal-achievement - task-success Self-esteem

		Self-Esteem scale Rosenberg, 1965	- ability to do useful things well - self-worth / -respect / pride - Self-satisfaction - having good qualities
12	Coping advice		

(Figure 2. - Conceptualization of interview protocol)

Identity is conceptualized and informed by the in-length described Identity Process Theory by Breakwell (Breakwell & Jamal, 2016). Continuity, self-efficacy and self-esteem are hypothesized to be affected by an ASD diagnosis and therefore will be investigated in the interviews. The *Rosenberg self-esteem scale (1965)* and the *New General Self-Efficacy scale (Chen & Gully & Eden, 2001)* are validated and reliable scales for the measurement of those concepts and served to inform the construction of the interview protocol as well as the category system for the qualitative content analysis.

Cooper, Smith and Russell (2017) showed in their paper that accepting one's autism reduces the chances of depression and anxiety, which is the theoretical basis for questions in the interview relating to the degree of acceptance of participants ASD diagnosis.

Public Stigma, as described in previous sections (see page 2), has negative effects on mental health. Furthermore, it can lead to internalized stigma, erode individuals social standing, diminish their self-esteem and recovery (Ritsher & Otilingam & Grajales, 2003). Therefore public and internalized stigma are investigated in the interviews as potential mediators between the ASD diagnosis and its effects on the identity concept. The concept of internalized stigma is informed by the *Internalized Stigma of mental Illness scale (ISMI)* (Boyd & Adler & Otilingam & Peters, 2014).

Disclosure, telling people in one's social environment about the ASD diagnosis, has the beneficial effect of reducing public stigma (Sasson & Morrison, 2017). For that reason the degree of disclosure of the participants to their social environment is explored in the interview. Psychoeducation in terms of educating the public about ASD can additionally help to reduce social stigma (Sasson & Morrison, 2017). Therefore, psychoeducation of the public is hypothesized to reduce the negative effects of stigma on the identity concept.

Finally, questions 1-3 are designed to ease the participant into the interview and gather background information relevant for the following concept-targeting questions. Question 12 is meant to round the interview up on a positive note as well as giving the participant the chance to raise any ideas of important aspects when dealing with one's ASD diagnosis which are not taken into account in this paper, with the goal to inform further research and ultimately clinical or personal practice.

Due to the theory-guidedness of the investigated concepts, concept validity can be ensured. For a one-on-one mapping of the investigated concepts to the questions within the interview protocol, see *Appendix 1* for the full interview protocol and *Figure 2*. The interview transcripts of participant 1 and 2 can be found in *Appendix 2* and *3* respectively.

Method of data analysis

The method to analyse the interviews is the qualitative content analysis by Philipp Mayring (2014). The particular method suggested by Mayring, which is most suitable for this research, is the *Content Structuring / Theme Analysis* approach, a mixed procedure (Mayring, 2014, pp. 104). Why this approach is appropriate for this specific research is summarized well by Mayring (2014, pp. 104):

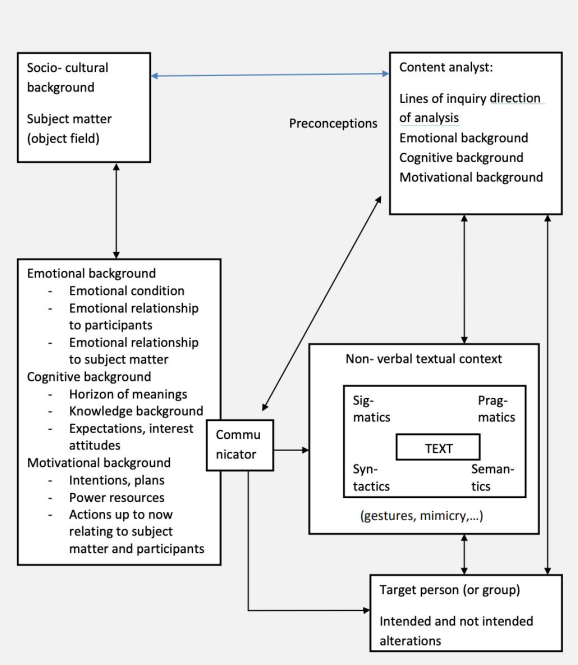
> *"... selective analysis of subject matters or attributes of the text [using] a bottom-up strategy (we would call it inductive) and a top-down (deductive) strategy. [The] aim is to identify themes as categories, and to analyse frequencies and contingencies of the content categories."*

The theme analysis following Philipp Mayring (2014) is applied in this study because of its strengths in combining a qualitative, interpretative analysis of the text material with a quantitative co-occurrence and frequency analysis to quantify the mentioning of investigated concepts and their relationships to each other. This mixed-methods approach is suitable for research crossing the boundaries between psychology and philosophy, because the method is content and subject sensitive while allowing to apply concepts deductively in order to test theories (Elo & Kyngäs, 2008). In this case the relevance of IPT principles when being diagnosed with ASD. Furthermore, while analyzing the transcripts, any concepts of importance which were not inferred from the theory can be captured by inductively creating categories in the process.

The analysis organizes the spoken words in the interview into fewer, comprehensible categories of importance in this investigation. Moreover, the method of a qualitative content analysis fosters understanding of the meaning of the interviewees responses and aids in identifying critical processes. The aim of this thesis is to do precisely that; to understand the processes leading to effects of an ASD diagnosis on the identity and identifying important concepts in dealing with one's autism well. Therefore a qualitative content analysis is more appropriate for this aim as compared to a purely quantitative method.

Direction of data analysis

The direction of the theme analysis will be to investigate the emotional, cognitive and motivational reactions of the participants towards the diagnosis, to the social reactions to their diagnosis and their subsequent effect on their identity concept. This direction of analysis is specified by Philipp Mayring (2014, pp. 49) in Figure 3. Specifically, the relationship of the participant to their autism, the emotional effect, the cognitive meanings, the knowledge, expectations and attitudes towards the diagnosis and their intentions, plans, actions and motivational resources for actions to deal well with the diagnosis are of interest.



(Figure 3. Direction of Analysis - Philipp Mayring (2014, pp. 49))

Following Mayring's qualitative content analysis (*Figure 4.)*, the structuring method to the interviews was adopted (Mayring, 2014, pp. 95), in which categories were constructed beforehand, following the literature review as the theoretical framework, the research hypotheses and the validated scales and research papers *(Figure 2.)*. This category system was deductively applied to the interview transcripts and occurence and frequency of the categories are stated as well as correlations between them, with the co-occurrence tool of the software Atlas.ti. The minimum text component which can count as one category was defined to be a subset of a sentence, whereas the maximum unit falling within one category was defined to be the full answer to one of the questions. Taken that the theory driven approach to the interview analysis could be insufficient to capture the important aspects within the participants answers, inductively emerging categories from the text were captured and their potential meaning will be discussed later on.

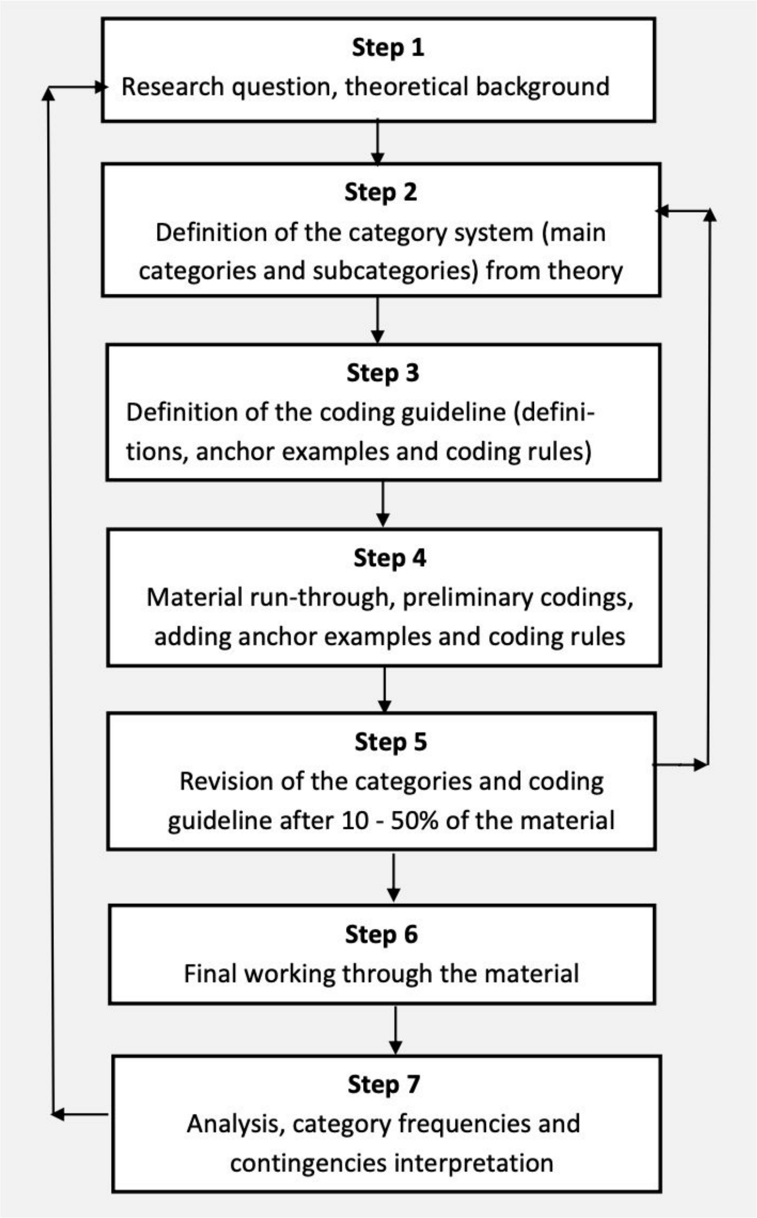


Figure 16: Steps of deductive category assignment

(Figure 4. - Procedural model of a structural content analysis - Mayring, 2014, pp. 96)

Category system conceptualization

Appendix 4 displays the code book, defining each category's content, stating an anchor sample; a typical example from the material to illustrate the character of the category, and the coding rules, if necessary. Coding rules are defined given the case of ambiguity of a particular category in respect to the other categories, in order to draw a clear separating line between them.

Furthermore, inductively emerging categories from the material are visualized in *Appendix 4*. by being written out in *italic* letters as compared to theory driven, deductively applied categories.

Additionally, the codes were grouped into a *positive impact* group *(C1, C3, C5, C7, C10, C15 - Appendix 4.)*, describing the codes which appeared to have a positive impact on the overall wellbeing and the identity concept of the participants, as well as a *negative impact* group *(C2, C4, C6, C8, C9, C11, C12, C16 C17, C18 - Appendix 4.)*, including the codes which had a negative impact on those factors, and a *neutral code* group *(C13, C14, C21, C22, C23, C24 - Appendix 4.)* which includes variables that do not have an inherent value but gain the positive or negative impact on the participants in combination with other codes. Additionally, the group *challenges & coping (C19, C20 - Appendix 4.)* was created after the analysis, in order to capture important aspects in dealing with one's autism, which are not relevant for the identity model developed here but that further research could benefit from. The codes *disclosure* and *no disclosure* are part of the neutral group due to their varying impact on the participants when combined with other codes. The total number of codes in each interview can be reviewed in *Appendix 5* Co-occurrences of codes can be reviewed in *Appendix 6* and full reports of the interview codings according to categories in *Appendix 7.*

Results

Acceptance - positive impact group

The code acceptance in the first interview co-occurs most often with the neutral code of a DCD diagnosis. Because the first participant was diagnosed with a Developmental Coordination Disorder (DCD) when he was 6 years old he indicated that he identified with this diagnosis for all his life, until he received an ASD diagnosis at the age of 24.

> *(1:30) "See, I was satisfied with my "DCD" diagnosis. I did feel different from others, that's why I got the diagnosis (DCD). One of the symptoms is feeling out of breath, like you're choking when you are in big groups. I definitely have that. I also have issues with being touched, I only like it in very specific situations, that I don't want to go in detail about now. I don't like eye contact either, but that's it. I was fine with it, that is who I am."*

This quotation was coded with acceptance because he indicates being satisfied with the diagnosis and identifying with it, therefore accepting it as describing a part of his identity accurately.

Participant 2 showed acceptance in relation to the ASD diagnosis code most often. He was diagnosed with 10/11, when he was in 5th grade. He accepts the diagnosis as part of his identity, as stated when asked about the meaning of ASD for his sense of self and his life:

> *(3:97) "I would say it is a big part of my life. Yes, I think it is part of my identity. The parts of autism that I recognize in myself are definitely part of who I am."*

It can be summarized that participant 1 and 2 both accept the diagnosis they were given at an early age, because they feel like some parts of the diagnosis describe aspects about themselves validly. The difference is that the participants are accepting towards different diagnoses, DCD in the case of participant 1 and ASD for participant 2.

> *(3:99) "Parts of myself I can recognize in the category of what autism is, so the way I think about it is that it explains parts of myself."*

Continuity - positive impact group

Furthermore, the diagnosis of DCD did not threaten the sense of continuity of participant 1 because he recognized the difference between himself and others as being the specific symptoms described by the diagnosis;

> *(1:32) "I did feel different from others, that's why I got the diagnosis (DCD). One of the symptoms is feeling out of breath, like you're choking when you are in big groups. I definitely have that. I also have issues with being touched, I only like it in very specific situations, that I don't want to go in detail about now. I don't like eye contact either… ."*

Participant 2 did not feel threatened in his sense of a continuous identity either, when receiving the ASD diagnosis.

> *(3:21) "I think I kind of grew into it. It was not a clear line for me. I imagine someone getting a cancer diagnosis and being shocked. It was not like that for me. The more I understood about it, the more I felt like it was just something I had."*

Similar to participant 1, participant 2's identity was not disrupted by the diagnosis because he did perceive himself as being different from other children as well before the diagnosis:

> *(3:22) "Yes I think so. Especially looking back, when I was young I think I didn't have many friends and I didn't like to go to sleep overs, or playdates or parties later in high school. So I think that was a clear indication that there was something going on, and then I also had panic attacks and intense anxiety. (...)*
> *It was a mixture of things, the autism, the anxiety. So I have an autism diagnosis but also a generalized anxiety disorder diagnosis. I think I was never comfortable in school, I had stomach aches in the mornings, that I remember really clearly.*

Receiving their respective diagnoses provided participant 1 and 2 with more insight and an explanation for what they were experiencing instead of threatening their identity concept.

No acceptance - negative impact group

In the case of participant 1, the code of no acceptance had a high co-occurrence with the neutral code *ASD Diagnosis*. This is due to the fact that he received another diagnosis when he was younger, that he identified with and accepted to be part of himself. He also indicated that he did not accept the diagnosis of ASD because of the way that it was presented to him, the category of ASD did seem too generalized and large in its symptomatics for the participant to recognize himself as belonging to the category.

> *(1:104) "There are only 3 things you need to know about me, and those are not the diagnosis ASD but the symptoms I told you about. They are part of me, ASD is not."*

He explicitly criticises the broadness of the category as posing an issue for him because he does not recognize all of the symptoms belonging to the category, but only a few, which were for him better captured in the more narrow category of his previous diagnosis.

> *(1:67) "Autism is a spectrum and I for myself only recognize not liking touch, eye contact and big crowds, the rest doesn't apply."*

Participant 2 in comparison displayed an overall accepting attitude towards the ASD diagnosis, which was never changed in his case. Nonetheless, he voices acceptance of parts of the symptomatic pool of the autism category only.

> *(3:99) "Parts of myself I can recognize in the category of what autism is, so the way I think about it is that it explains parts of myself."*

Disruption - negative impact group

Receiving the ASD diagnosis caused a disruption in the identity of participant 1 because his previous diagnosis, which he identified with, was changed.

> (1:17) *"My entire life I was told that I don't have ASD but DCD but then, here, they told me that DCD did not exist anymore. It was apparently now considered to be part of ASD, so they did a brief test, like 30 minutes, and then said "Yeah, you got it." It still feels like I don't."*

On further request of the details given to him in the diagnostic process he stated that he did not receive more details, which is interpreted as having strengthened the effects of disruption.

> (1:22) *"They literally told me because of budget cuts "DCD" doesn't exist anymore, so they put it on one pile." "(...) they just said; now we can give you a counsellor"*

The lack of person-specific details, that he could have identified with, contributed to him perceiving the ASD category as too broad to accept it as a part of his identity. In the interview he voices irritation about the lack of details and explanations offered to him as well as anger about the sudden disruption of his identity in the form of changing his diagnosis.

Participant 2's perception of self was not disrupted by the ASD diagnosis, as displayed by the quotations in the 'continuity' section.

Social factors

Breakwell empathizes the psychological as well as social influences on the identity concept of a person (Breakwell & Jaspal, 2016, p.5). According to him, social representations influence the determination of the contents of one's identity as well as the values assigned to the contents. Therefore it has been hypothesized that social factors, meaning reactions and attitudes of the social environment of an individual will influence the identity components of self-efficacy and self-esteem.

Social Stigma - negative impact group

First of all, it is important to notice that participant 1 experiences a lot of social stigma around the category of ASD which he indicated to be mediated by a *lack of psychoeducation*.

> (1:66) *" I get frustrated and annoyed with the media because they take the typical picture of a little boy staring into a snow globe and say that is what autism is like. The truth is that there are so many people falling into the category of autism and they can't be generalized to the picture the media portrays."*
>
> *(1:167) "I had a teacher once who was talking about traits of ASD and then said: "I should know what that means, since I have a diagnosis myself.". I didn't expect that so it just shows that the diagnosis is also applied to people that don't have all the symptoms and that don't appear like they have ASD at all."*

The quotations indicate that the participant feels like the stigma about the autism category is mostly influenced by public media, which portraits autism in a non-informed and generalized manner.

Participant 2 supported the issue of the media portrayal of autism as being too stereotypical and not illuminating the nuances within the population of diagnosed individuals.

> *(3:41) "It is something I still struggle with because people don't understand what it really means, they don't understand that autism is so different for everyone. They have a stereotypical perception of it. Some time ago there was a video on youtube of a kid and you saw what he sees, strong lights and intense colours. It is something I also experience, maybe not on that level though."*

Furthermore, participant 2 agreed that social stigma and stereotyping in the media is influenced by a lack of psychoeducation of the general public.

> *(3:48) "Yes I think so because of movies and tv shows that show it in a certain, very extreme way. I assume that the image people have of autism is influenced by that. So I think they judge more if they only know that image but the more they know the more they can see that we are all the same - we are all people."*
> *(3:51) "So yes, I think the less they know the more judgemental they are."*

Discrimination - negative impact group

Social stigma leads to discrimination, as the participant reports:

> (1:93) *"People only listen to the media and the stereotype of Autism shown there. They would think "Oh, no let's help that person.", but then treat you like a child. I had a friend who disclosed her ASD in school and that is what happened to her; she was treated like a kid."*

Experienced discrimination and social stigma had severe negative consequences for the participant and people close to him, that experienced it too. He reports that he was convinced by his mentor and dean (in his first study; "LVO") he would not be able to become a teacher when he disclosed his DCD diagnosis.

> (1:84) *"...it was discrimination and I should've fought it. Maybe I should have but back then I was too low mentally to fight against it."*

Discrimination led the participant to internalize the negative affect towards his diagnosis and made him stop believing in his abilities.

Discrimination as a code did not apply to participant 2. In his interview a code emerged inductively which is worth presenting and was applied to interview 1 as well in a second analysis.

Insight - positive impact group

Insight into one's characteristics, likes and dislikes, co-occurs for participant 1 with the acceptance of his DCD diagnosis. The diagnostic details provided insights into himself, leading him to accept the diagnosis as well as himself.

> *(1:126) "One of the symptoms is feeling out of breath, like you're choking when you are in big groups. I definitely have that. I also have issues with being touched, I only like it in very specific situations, that I don't want to go in detail about now. I don't like eye contact either, but that's it. I was fine with it, that is who I am."*

Insight and acceptance additionally lead to higher self-efficacy in the sense that participant 1 has a better understanding of what he needs in certain situations, making him able to deal with them.

> *(1:11) "I do meet people to play games with, and I go to the "Spiel Essen" each year and to the medieval events "Ter Apel". I don't like big crowds but when I am there I focus on the things I am interested in (the games) and that makes it easier to be around a lot of people."*

Insight functions as a protective mechanism for participant 2 against stigmatizing attitudes conveyed by the media.

> *(3:71) "I don't feel stigmatized by the media because I am really self-aware, I know what works for me and what doesn't and I learned to talk openly to people around me and ask for what I need. I learned that that is the best way to cope with it. So I don't feel stigmatized."*

Asking people openly for what one needs is an indicator of self-efficacy and self-esteem. The emerging code of insight seems to be an important mechanism for participant 2 to know about himself, to accept himself and followingly be able to not feel stigmatized and voicing his needs unapologetically.

Moreover, the code co-occurred with *acceptance* mostly, indicating that through the aspects of the ASD diagnosis he recognizes in himself, he gains insights into himself and can accept himself, as well as for participant 1 in regards to his DCD diagnosis.

> *(3:28) "I think it is a part of me and I know how to live with certain things coming with it. And I know it prohibits me to do certain things. At a certain point you learn that some things are better for you than other things. I don't know, it's just my life. And it is a big part of my life but I don't say: "I am Joris, I have Autism." It's not something I write down on my ID card."*

Disclosure / No Disclosure

The willingness of participant 1 to disclose his diagnoses is influenced by different factors. The reason to *not disclose* his autism diagnosis was largely affected by his *lack of acceptance* of the category.

> *(1:73) "I never tell anyone about my ASD diagnosis, I don't feel like I have it so why would I say it?"*

Another indicator for *acceptance* of one's diagnosis, increasing the willingness to disclose it to others, is the fact that the participant used to disclose his previous diagnosis (DCD), which he identified with.

> (1:75) *"With DCD I did tell people around me, but usually I just told them that I have issues with eye contact, touch and big crowds. That was never an issue for anyone"*

Interesting in this quotation is that he chose to mostly disclose the symptoms he recognized for himself, instead of revealing the category itself. This strategy has been met with understanding and *social support*, as indicated by the last part of the sentence.

The strategy of disclosing his symptoms instead of the category results out of his (direct and indirect) experiences with disclosing the category of his diagnosis itself.

> (1:78) *"But in my first study I disclosed the DCD diagnosis to my mentor because I wasn't doing well, I had too little ECTS and wouldn't make eye contact with people. So I told him that DCD is the reason. He said that people who have this cannot become teachers and really talked me down."*

> *(1:60) "I know someone, he would get psychotic when under stress, and when he disclosed himself he was not helped at all, he was discriminated against and it ended really bad for him, he had to do an extra year of studying just because they thought he wasn't able to do it even though he was."*

The participant summarized the reasons for not disclosing his autism in the following way:

> (1:101) *"Because of the stereotypes in the public media I think it is better not to disclose ASD because it would change people's attitudes in a negative, stigmatizing way. It is difficult to change the mainstream image of ASD so it is better if people don't know otherwise they will apply those stereotypes on you."*

Participant 2 has a similar strategy when disclosing his autism as participant 2 used to have when disclosing his DCD. He reported disclosing his autism whenever he feels like it necessary or beneficial for everyone involved. He describes disclosure as helping others, as well as himself in dealing with his, or even others' autism.

> (3:32) *"I know that autism is a spectrum and it is really wide, a lot of different problems have the same label. I am not really socially awkward for example but my brother is. He doesn't talk about his feelings, I probably do it too much. I know that people have different forms of it.*
> *I think I can pick it out more easily, when I see people having social problems, sitting weirdly or not knowing how to respond or behave, I know how to respond to people like that."*

Participant 2 furthermore highlights the importance of knowledge about autism for disclosure to be beneficial. He discloses himself when he needs something specific in order to function well in a given context.

> *(3:81) "Autism matters more when people expect things from you, if they want something from me and it does not go the way they want it to. When those issues are related to autism I can explain it to them in that way, that there are certain things about me that should be taken into account."*
> *(3:75) "I try to explain it accordingly, so people get a sense for how I work. I tell them what applies to me and what I need in my environment. I don't drop my autism out of thin air but in the context of what I need. But then I do tell them, in a practical context."*

In those contexts, from participant 2's perspective disclosure leads to social support, as compared to participant 1's experiences with disclosing autism. Participant 2 discloses his autism in a practical context and refers to the specific symptoms applying to him, similar to how participant 1 used to disclose his DCD diagnosis.
Participant 2 additionally reports that in his field of occupation (computer science), people know a lot about autism and generally perceive autistic people as rather beneficial for work.

> *(3:52) "It is usually more the case that if I react a certain way and it can be explained with my autism, I explain it. So I haven't been discriminated against because of my autism.*
> *My field of study is also a very good environment for people with autism."*

Social Support - positive impact category

Even though the participant does not accept, and does not disclose his autism, he recognizes that *receiving a diagnosis* was needed for him:

> *(1:37) "So, considering the pro's and con's, there are more benefits to me having a diagnosis because it allows me to get the support I need."*

By that he means individual therapy, which he expressed to be needing due to *bad mental states.* These mental states that he described occur most often in his life during times in which he experiences a *lack of social support* when he needs it to reach goals and overcome challenges.

> (1:44) *"I literally lost faith! That is where the mental damage started. I was so stressed to find something, I contacted so many companies myself and no one helped me, the phone was never answered."*

Participant 2 reports that social support he receives is positive for him. Therapy provides him with the conditions he needs in order to feel good and work well, as well as providing him with valuable insight. The social support helps him to know, help and accept himself.

> *(3:93) "I talk to my parents or my friends about issues, I like to talk to my therapist here as well because it adds another layer of reflection and insights."*

> *(3:94) "I am doing PMT therapy now (Psychomotor therapy), it helps me to understand what I am feeling in my body because I am usually feeling a lot and I can overfocus on that. My mind then jumps to the conclusion that I am probably sick. So PMT helps to understand what I am feeling."*

> *(3:96) "CBT helped me a lot for my anxiety and I am still keeping the mechanisms that I learned there. Social skills training helped me as well but I could not practice it a lot now because of Corona."*

Furthermore, the knowledge and understanding of his family about autism results in support for him.

> *(3:3) "We're close and they are understanding, they also know my brothers and my diagnoses. It's generally well understood in the family and it gives a certain freedom for when we're away with the family in a large group for a weekend, that*

> *sometimes I am not joining activities because I need some time alone. So that's very nice."*

As for participant 1, receiving a diagnosis was important for participant 2 to obtain the mental health support he needs on an institutional level.

> *(3:16) "That is one of the reasons why we went to another autism center (for children). And there I got a proper diagnosis, I got some training and my parents got group therapy with other parents of children with autism.*
> *And since then I've been to mental health institutions every year for some kind of reason."*

In his case, even his family benefitted from his diagnosis in the sense of receiving support, training and psychoeducation.

Self-efficacy - positive impact group

Participant 1 feels supported by his social environment, indicating good relationships to his parents, grandmother and having multiple friends. This seems to enhance his *self-efficacy* and *self-esteem* and made him feel like he was able to deal with otherwise challenging situations.

> *(1:11) "So about clubs and activities, I don't feel very comfortable in big groups so I've never really been part of a club but recently I discovered a side with people that enjoy the same interest (...). I do meet people to play games with…"*

Even though big groups and social gatherings pose a challenge for him, he perceives himself as able to face that challenge when given the social support of friends and people that share his interests.

Participant 2 inhibits the view of facing challenges as well as participant 1, indicating a high degree of self-efficacy. Like participant 1, he learned coping mechanisms that help him in challenging situations:

> *(3:67) "But if I can focus on one thing and I am sheltered enough from outside noises I can focus really well and do a lot of work. I need to have the conditions to deal with it though."*

When he uses strategies that he has learned throughout his life, he feels secure and able to attain his goals, to work well and contribute to society.

Self-esteem - positive impact group

In general there was high co-occurence of the concepts of *self-efficacy* and *self-esteem* in both interviews. When participant 1 felt in control of his life and able to attain a goal, which he ultimately did, it made him feel good about himself.

> (1:52) *"We started with over 200 students and in the end 20 of them graduated. One of them was me though, I just wanted to be done with it so I succeeded."*
>
> *(1:117) "It also seems to get better, as a child I never made eye contact with anyone, Now I subconsciously try to do it more often and I think it works."*

Self-efficacy is for participant 2 mostly co-occurrence with self-esteem as well, supporting the finding from the first interview that being able to attain goals and face challenges, partly by using coping strategies, can lead to intrinsically feeling good about oneself. This is supported when participant 2 talks about programming, something he enjoys doing and is good at:

> *(3:58) "That is a part of logic and it is something I can generally do really well so I do see it as a benefit. Being focussed on doing your job and wanting to do it well, and thinking abstractly really helps as well when programming. And those are positive aspects of autism."*

Self-efficacy for participant 2 co-occurred often with the code of insight, he reported having learned to understand himself better and to structure his life in a way that made him feel good, leading to self-efficacy.

> *(3:85) "And to make sure that things which require a lot of energy for me, like driving a car, are well planned. I need to make sure to get enough rest. I need to know what I can do and can not do and plan it."*

He revealed moreover how he learned those necessary skills of efficiency:

> *(3:88) "I think most of them I experienced myself. And I believe that is also the only way to do it. To just experience on an energy level what is good for you and*

what is too much. And when you step over a boundary you notice it afterwards and then reflect on what was too much and learn from it.”

Discussion of results

Acceptance and Continuity

Acceptance and Continuity have a high co-occurrence for both participants. For participant 1 in regards to the acceptance of his DCD diagnosis and for participant 2 for his ASD diagnosis. Both of them, in regards to their respective diagnoses received at a young age, perceived the diagnoses as matching their previous perceptions of themselves (1:32, 3:22, 3:27) in terms of the described symptoms. This supports hypothesis 2, as well as indicating that a sense of identity continuity across a diagnosis enhances the ability to accept it.

Further support for hypothesis 2 is provided by the negative example of participant 1's experienced disruption of identity through the ASD diagnosis when he was 24/25, when before he identified with the DCD diagnosis. He voiced irritation and anger about the disruption as well as his inability to recognize himself in the symptoms that were presented to him in an ASD psychoeducation course (1:56). Followingly, it underpins the notion that disruption has negative effects on one's identity concept as well as hindering the process of accepting the diagnosis into the self (1:22).

Accepting the DCD diagnosis into participant 1's identity led him to accept those parts of himself as well, aiding self-esteem (end of quotation 1:30). The provided insight led to higher self-efficacy due to understanding his needs better and acting accordingly (1:11). The same applies to participant 2 (3:28).

The positive effects of acceptance and continuity, hypothesized in 1. and 2., are supported by the two interviews. In specific, the positive effects on one's identity are caused by the insights which the diagnosis provides. Specific diagnostic details which one can recognize in himself, foster an understanding of previously intangible ways of behind (behaviours, thoughts, cognitions) and a way to talk about them. This aids self-efficacy and self-esteem. The relationship between the two appears to be such that higher self-efficacy through more insight leads to being realistic with one's goal setting and followingly attaining the goals. This provides positive feedback about oneself, increasing self-esteem (1:52, 1:117, 3:58, 3:85)

Social factors

Both participants agree that the way specifically the media depicts autism is stereotypical and reductionistic (1:66, 3:41, 3:48, 3:51). They report the mainstream media to be the main influence on people's perception and understanding of autism, which leads to stigmatizing attitudes. The lack of psychoeducation, or awareness of the general public about autism as a category is therefore supported to contribute to public stigma, as hypothesized in 3. and 4.

Participant 1, only, supported the hypothesized negative effects of social stigma - through the following discrimination (1:93) - on his self-efficacy. He was discriminated against due to his DCD diagnosis and was convinced by the attitudes of his social environments that he was not able to finish his ‘LVO’ study (1:84). This supports the hypothesis that stigmatizing attitudes of the social environment can reduce the belief in one’s own abilities.

Disclosure / no Disclosure

First of all, to disclose or not disclose one’s autism logically depends on the acceptance or non-acceptance of one’s own diagnosis (1:73). But furthermore, the willingness to disclose is also influenced by social factors. Due to the stigmatizing attitudes held in the public around the category of ASD (1:101) it seems more beneficial to disclose one’s symptoms rather than the category itself. This is drawn from the interviews (1:75, 3:52, 3:75) to be done in a practical context to explain one’s needs and behaviours, and leads to understanding of the social environment.

The willingness to disclose oneself followingly is connected to the lack of psychoeducation leading to social stigma. By disclosing one’s symptoms, the individual diversity within the category is accurately captured, thereby not bearing the potential to generalize and apply stereotypes to the person, but instead recognizing the individual identity.

In that case, the results contradict hypothesis 4 partly, as disclosure does not necessarily reduce social stigma. This is only the case of a thorough understanding by the environment of the diagnosis (3:3, 3:32, 3:65). The relationship between disclosure and social support is bidirectional; disclosure can lead to social support, given that the social environment is supportive already, and thereby increases the willingness to disclose.

Self-esteem and self-efficacy

Good relationships with, and good understanding and support by the social environment of a person with autism generally has positive effects on the individual. Specifically, self-efficacy is increased due to the providence of security to face challenges (1:11, 3:3, 3:67). As discussed earlier, self-efficacy leads to higher self-esteem. These findings support hypothesis 3 and 4.

Receiving a diagnosis

Receiving a diagnosis is important to discuss because of its effects on social support. Receiving a diagnosis is in many regards necessary for someone with mental health issues in order to acquire not only the understanding of one's social environment, but institutionalized support. Both of the participants recognize that they needed a diagnosis in order to receive therapy, counselling and social services which helped them both in increasing their self-efficacy and self-esteem (1:37, 3:93, 3:94, 3:96).

Insight

Insight as an emerging category was not considered before but demonstrated high importance from the content analysis. Insight as understanding oneself (behaviours, emotions, cognitions) is supported by institutionalized support as well as being provided with a diagnosis and appropriate psychoeducation (1:126, 3:28). Insight emerges as a supportive mechanism for self-efficacy, self-esteem and protects from internalizing stigma (1:127, 3:71).

Moreover, insight results in finding coping mechanisms, which will be discussed in the following section.

Limitations

This study is an individual and identity based approach to the question of how to deal with one's ASD diagnosis. Therefore it can not be generalized to a broader population. Furthermore, there are multiple aspects, as discussed previously, which are important in further research about Autism and are not discussed in this paper in detail.

This paper illuminates the underlying, identity based processes which need to be considered when an individual is given an ASD diagnosis. The sample of research is limited due to my status as a bachelor student. In this context, I thank Kirstin Greaves-Lord for making this project possible. This paper should be regarded as a pilot study for the following project "Omgaan met het (eigen) autisme".

Future research

Concerns

Concerns of both participants were voiced about the media portrayal of autism. Interesting to note is that the issue was brought up as ASD being a very broad category in which symptomatics apply to individuals diagnosed with it different in quality as well as extent. This is mentioned by both of them to be problematic for their identification process with the category (1:99, 3:28, 3:32). It seems beneficial to dedicate some research on this issue.

Further concerns that should be regarded when treating or researching autism are concerns about social and/or partner relationships (1:64, 1:102, 1:108, 1:112). Solving those issues with building social relationships could be supported with social skills training, which both patients received. Both indicated it as being helpful, therefore it seems to be a promising approach to supporting people with autism (3:96).

Another concern drawn from the interviews is sensory overstimulation, which is part of the reason why the participants are not comfortable in social gatherings (1:102, 1:108, 1:112, 3:59, 3:86). Participant 1 indicated that for people with autism it would be helpful if there are alternative ways of establishing social relationships which are not related to places in which overstimulation is likely to occur. Those settings could be online gaming, platforms and communities with likeminded people, or events set up which are planned out to be less taxing on the individuals. Those alternative ways of socializing could be supported in social skills training by introducing people with autism to those options and to release the pressure of having to socialize in the common sense of them. This could be a point of departure for future research.

Coping / Support

Promising topics were brought up in the interview in regards to how to deal with one's own autis that could be beneficial for treatment and further research.
Focussing on one's interests, people that one is close to, one's own breathing when being overstimulated (1:12, 1:107, 1:117) is one coping strategy being mentioned. This can be summarized in practicing mindfulness as a way to calm oneself and providing insight (3:92). Furthermore, practical methods for reducing overstimulation provides benefits in work-environments (3:60, 3:64, 3:87).

All of these coping mechanisms require insight into oneself and being able to voice one's needs. To support people to develop insight, mindfulness seems promising.
Individual therapy benefitted the participant, too. Both of them stress the importance of the therapy form being tailored to the specific individual and stated that they can not be generalized to the broad category of people with autism.

Participant 2 reported positively on his CBT specifically for his fear related issues (3:40) and beneficial PMC therapy for intrinsic overstimulation (3:94).
It becomes clear that therapy is helpful in an individual approach to it, tailored to the individuals needs, symptoms, concerns and challenges.
In order to distribute these forms of therapy, both participants regarded centers like ATN as valuable (1:24, 1:29, 1:120, 3:10, 3:16)

Both participants indicated the importance of speaking openly to their social environment about what they need, once the insight is there (1:123, 1:124, 3:43, 3:83).
Treatment research should take this into account and focus on providing support for insight into one's own (not generalized) way of functioning and then provide behavioural therapy in order to teach the patients to be able to voice their needs. It is also beneficial to teach the patient practical ways of how to structure their days according to their needs (3:85, 3:88).

There is still a lot that needs to be done in order to support people with autism in their lives. The first step is summarized by participant 1:

> *(1:123) "I think one of the biggest issues is that there is still such a big taboo around mental issues, no one talks about it. I think that needs to change, people need to talk about their mental struggle more."*

This is what this paper, and the subsequent research project 'omgaan met het (eigen) autisme' attempts to do: give affected individuals a platform to speak up, voice their needs, their concerns and their advice.

Conclusion

Describing the categorical approach of the DSM-5 to diagnosing mental disorders has led to the conclusion that categories as the endpoint of a diagnostic process are inaccurate for capturing the diagnosed individual. A lack of awareness of the diagnostic, individual specific details can lead to public stigma. Public stigma can lead to internalized stigma and it has been hypothesized in this paper that the mechanism for this can be explained by processes of identity formation. The leading question of this paper was how an autism spectrum disorder diagnosis can affect the identity concept of an individual. Therefore, an individual research approach was taken in this paper. Breakwell's (Breakwell & Jaspal, 2016) *Identity Process Theory* served as the theoretical framework for the analysis of two participants with an ASD diagnosis. On the basis of this theory and other papers measuring investigated concepts, semi-structured interviews were conducted and analysed using the qualitative content analysis following Mayring (2014).

The analysis of the interviews revealed that a sense of continuity of one's self across the diagnosis leads to higher willingness to accept it. On the other hand, disruption of one's identity concept by the diagnosis has negative consequences for the identity concept and hinders the process of accepting the diagnosis as part of oneself. This is in line with hypothesis 2. Accepting one's diagnosis as part of one's identity was found to aid acceptance of oneself, leading to higher self-efficacy as well as self-esteem. Self-efficacy and self-esteem have a positive bidirectional relationship in the interview analyses. These findings support hypothesis 1. Furthermore, given continuity across the diagnosis and acceptance of it, the diagnosis can support insights for the individual.

The mainstream media depicts ASD in a stereotypical and reductionistic way, which lowers the understanding of the public for people with autism and the nuances within the category of ASD. Moreover, it can lead to social stigma and discrimination, which has negative effects on individuals self-efficacy and self-esteem. These findings reinforce hypotheses 3 and 4. Psychoeducation of the general public alleviates those negative effects.
If disclosure leads to social support, as hypothesized, depends on the understanding of the social environment of the ASD diagnosis. Therefore, psychoeducation of the public functions as a mediator between disclosure leading to social support, or to social stigma. Disclosure of individual-specific symptoms is most beneficial to raise understanding and social support.

Social support has positive effects on one' self-esteem and self-efficacy. Receiving a diagnosis is necessary to receive institutionalized aid, like therapy, counselling, skills training, etc. Furthermore, these supports can lead to heightened inside of the individual in their way of being (emotions, cognitions, behaviours). Insight is an important factor supporting self-efficacy, self-esteem, acceptance of oneself, and is a protective mechanism against internalized stigma. Additionally, insight can lead to the development of coping strategies when dealing with one's own autism, improving life quality.

Therapy in its various forms needs to be highly individualized in order to help people within the very broad spectrum of autism to deal with their own specific symptomatics of it. Promising starting points from the analyses were mindfulness practices, practical coping methods (like headphones), CBT therapy, PMC therapy, as well as social skills training. In order to distribute the suitable types of therapy to individuals, autism centers like ATN are beneficial as an institution to turn to.

In conclusion, Autism Spectrum Disorder is a very broad category with highly different individuals being part of it. People within the categories differ in the quality of their symptoms as well as in the extent to which they display them and in which contexts. The general population needs to be aware of those individual differences in order not to generalize and stigmatize individuals with the disorder. The same applies for treatment, which needs to be highly individualized and target person-specific issues. But over and above all, we need platforms for affected individuals to be heard, in the public just as well as in individual-centered research to get a nuanced understanding of autism spectrum disorder.

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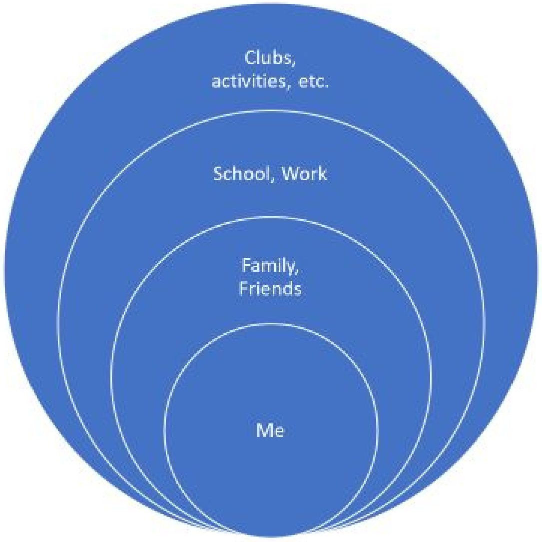
Appendix 1

Final Interview Protocol

1. Who are the people around you?



2. When did you get diagnosed with Autism spectrum disorder?
- how old were you?
- how did you get in contact with a psychologist?

________________________X____

Time >

3. How did you perceive the diagnosis and the information you were given in the process?
- what did the psychologist tell you, how much detail did he give you?
- did you feel like you were described well?

4. How did you feel about yourself / perceive yourself before the diagnosis?
- did you have a feeling you were different from other people?
- if so, what did you feel was different?

___________________<____X____

Time >

5. How did you feel about yourself afterwards?
- did you see yourself differently afterwards?
- did you struggle against the diagnosis?
- did you accept it?
- did you see positive / negative aspects of it?

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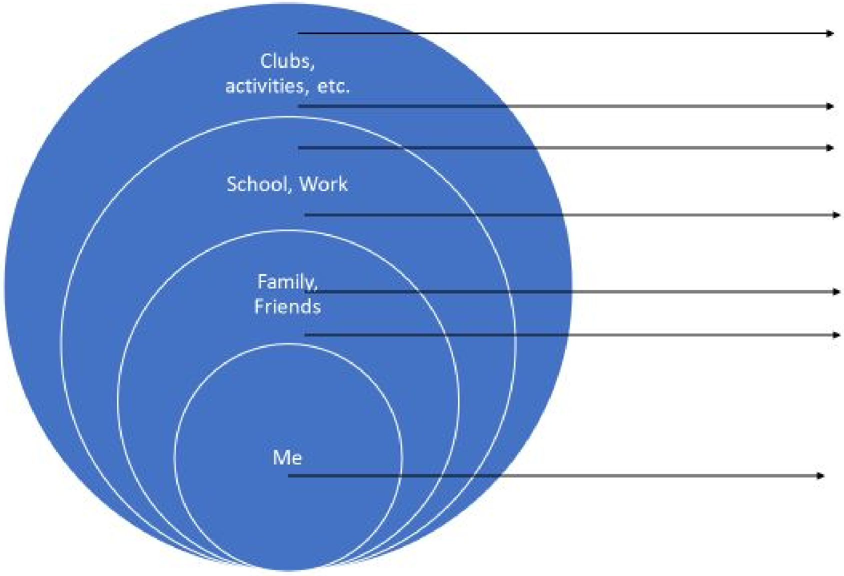
Time >

6. Do you think having autism is part of who you are?
- if so, would you call it a central aspect of yourself

7. Do you ever feel judged by people around you because of your autism?
- If so, how much do the people that judge you know about autism?



8. How does judgement by others make you feel about yourself?

9. How do you deal with the diagnosis when you meet new people?
- do you tell them about it?
- what do you tell them?
- How does it make you feel to tell people about your diagnosis?

Things I tell them right away	Things I tell them over time (in order of appearance)

10. Do you think telling people about your diagnosis changes the way they think about you and treat you?

Positive change	Negative change

11. How would you describe the way you cope with your autism for yourself?
- What are challenges for you and how do you deal with them?
- What aspects of your autism do you think you deal well with?

12. What advice would you give someone who just received their diagnosis?
- Which type of treatments did you receive?
- Which one(s) would you recommend to others and why?

Appendix 2

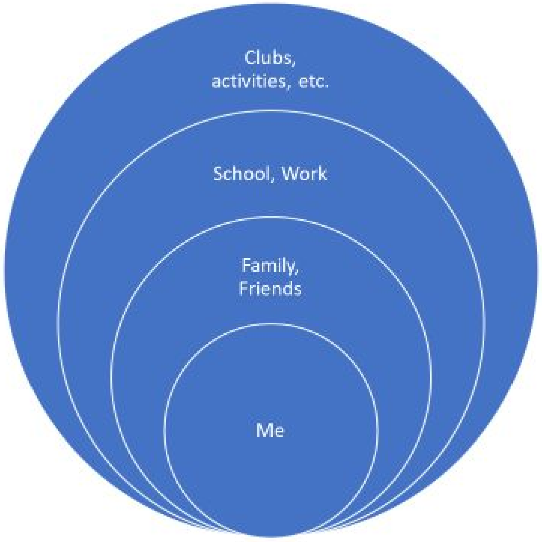
Interview Transcript Participant 1

Interview Participant 1
17.05.2020

Note:
The original interview questions served as a guideline, but were changed slightly to create a communicative flow. If the interview questions were changed, the questions asked are indicated by ***I:...****, whereas the answers of the participant are indicated by P:...*

1. Who are the people around you?

I:
Could you describe your social environment to me? Who are the people around you in your daily life? you can orient yourself on the graphic.



P:
I am not working, I just finished school. I go to my parents every weekend, before I started studying I lived at home but when I started I moved to groningen. I want to see my pet chicken at my parents home so I go there often. My social network is based around Groningen. I still visit

my grandmother as well, we sometimes go out together, but she unfortunately has the family heritage of having cramps.

My social network is mainly based on the city of Groningen.
I have one good friend in Groningen but because of Corona I haven't spoken to him in a while.
I have one good friend where my parents live, we often play board games together. There were a lot of people in my study that I would have liked to stay in touch with but the relationship disappeared, it is strange how fast that goes. I have two classmates that I am still in touch with, one of them I have a professional relationship with and one of them I have a social relationship with, I will see him this afternoon.
I got along well with the people in school, we were often complaining about the study together, nothing better than sharing a common evil to make friends. We shared a lot of inside jokes.

I think I will pretend as if there are no Corona restrictions when I talk to you about this, because the question is about average daily life. So about clubs and activities, I don't feel very comfortable in big groups so I've never really been part of a club but recently I discovered a side with people that enjoy the same interest (I don't want to disclose what that is). I do meet people to play games with, and I go to the "Spiel Essen" each year and to the medieval events "Ter Apel". I don't like big crowds but when I am there I focus on the things I am interested in (the games) and that makes it easier to be around a lot of people.

2. When did you get diagnosed with Autism spectrum disorder?
- how old were you?
- how did you get in contact with a psychologist?

______________________X____
_

Time >

I:
Could you describe to me the process of getting diagnosed with Autism Spectrum Disorder?

P:
Okay, this is where it will get weird! I showed some signs at a very young age, so my mother took me to a psychologist, I guess she was worried because I wasn't like the other kids. I received a "DCD" diagnosis…

I:
Sorry to interrupt, but how old were you back then?

P:

I was 6. Then, when I did my teacher study ("LVO"), I was 21/22, my mental state went bad and I had to quit because it was too taxing. I actually stopped doing anything for a while. So I was at home for 2 years and my mental state dropped, I don't want to go in detail, so let's just say it got really bad. Then I finally ended up here, at "ATN". My entire life I was told that I don't have ASD but DCD but then, here, they told me that DCD did not exist anymore. It was apparently now considered to be part of ASD, so they did a brief test, like 30 minutes, and then said "Yeah, you got it.". It still feels like I don't.

I:

Could you go into detail a little bit about how you got into contact with ATN and how old you were?

P:

I was about 24/25, now I am 30 years old.

I ended up here (at "ATN") because I wasn't in a good mental space. My mother is a social worker, and I think she noticed signs of a troubled teenager. Because she is my mother she couldn't help me herself so she asked a colleague, but it was not her area of expertise. She then got referred to "talent-school" and they advised her to take me to ATN.

3. How did you perceive the diagnosis and the information you were given in the process?
- what did the psychologist tell you, how much detail did he give you?
- did you feel like you were described well?

I:

Okay, and then when you got the diagnosis here, how much information did they give you, what did they describe to you about your symptoms?

P:

They literally told me because of budget cuts "DCD" doesn't exist anymore, so they put it "on one pile".

I:

Didn't they explain the concept of ASD to you?

P:

No, they just said: "now we can give you a counsellor". She was really great though, she helped me a lot, also with studying, I actually miss her. She had to stop due to something, and I finished my studies now.

4. How did you feel about yourself / perceive yourself before the ASD diagnosis?
- did you have a feeling you were different from other people?
- if so, what did you feel was different?

__________________<____X____
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Time >

P:
See, I was satisfied with my "DCD" diagnosis. I did feel different from others, that's why I got the diagnosis (DCD). One of the symptoms is feeling out of breath, like you're choking when you are in big groups. I definitely have that. I also have issues with being touched, I only like it in very specific situations, that I don't want to go in detail about now. I don't like eye contact either, but that's it. I was fine with it, that is who I am.

5. How did you feel about yourself afterwards?
- did you see yourself differently afterwards?
- did you struggle against the diagnosis?
- did you accept it?
- did you see positive / negative aspects of it?

______________________X____>_________________>_______________>_______________
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Time >

P:
I do "fight" with the ASD diagnosis in the sense of I don't accept it. From time to time I think 'why can't I be normal', but very rarely. Mostly I am okay with not liking big groups, eye contact and touch. But then the diagnosis they gave me, that fit me, doesn't exist anymore because of money? I don't recognize myself in the ASD diagnosis, I had psychoeducation about it and they showed us slides with symptoms, about what ASD is. And I don't recognize any of it. I don't have trouble reading people's emotions, I have no trouble understanding people or making jokes, or understanding sarcasm. I was told that people with ASD, so including me, have major issues with social situations, but they made it seem a lot harder than it is for me. So I don't recognize myself in it. I've also never experienced sensory overstimulation. I still don't feel like I have it (ASD).

I never really fought against the diagnosis though because it gives me so many benefits, I am happy with therapy, it 'keeps me alive' mentally. But I do mentally struggle with the diagnosis. I go into defense mode when I hear about it, because I don't see myself that way.

6. Do you think having autism is part of who you are?
- if so, would you call it a central aspect of yourself?

(This question was skipped because the answer was included in the previous answer.)

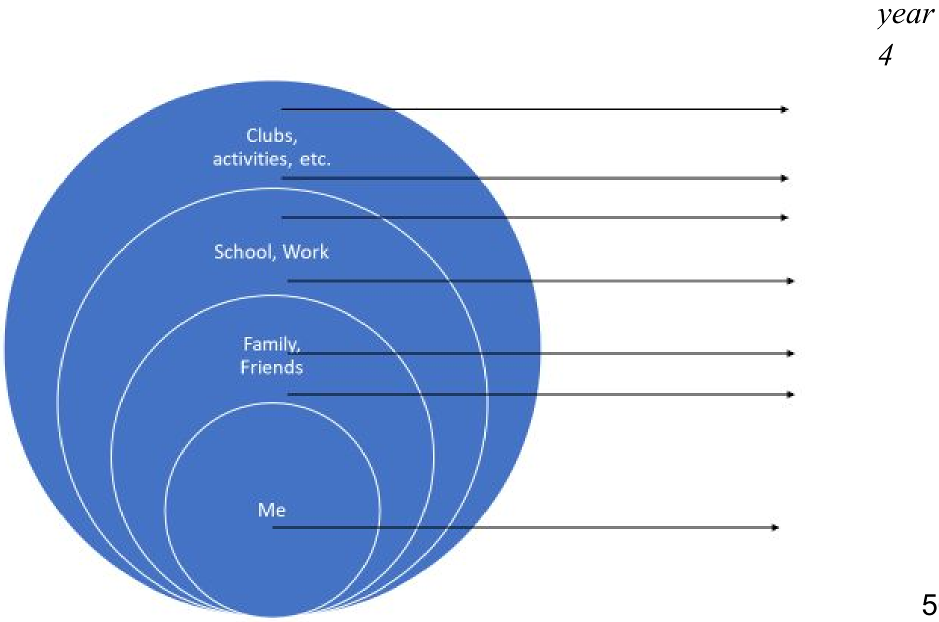
I:
Can we go back to your issues with your study? If you don't want to go into detail it is okay and you can stop the answer any time you want. I was wondering if you could explain to me why your studies were so bad for your mental health?

P:
Yes, the teacher study I did was just less of a study and more like a bootcamp. We had exams and papers and classes and projects to do all at the same time. It was just too taxing. Also for my classmates, people started crying and left the study often because it was too much. Every two weeks we'd have to meet our "mentor" and present our grades and he would say: "Only above 7 points? That is not good enough, you can do better, that is a bad grade…!" So on one point it was too much and I was done with it. I don't understand the logic, he made me feel like I was not good enough, like I wasn't able to do the study.

In my next study, I was only the second generation of people doing it. So no one knew how things worked, the communication was really bad and there were internal fights that I can not say too much about. There was just a lot of struggle and a lot of classes that didn't make sense. And then we had to do an internship. For 7 months before there was no communication and information about it, except that they said they would help us with it. And then 1 week before it started they said they wouldn't help us anymore and I literally lost faith!

That is where the mental damage started. I was so stressed to find something, I contacted so many companies myself and no one helped me, the phone was never answered. I live in an autism community so I decided to ask the "begeleiders" (translate = mentors) for help. When they called the company they did answer and I finally got an internship within a week.

The internship was bad then too, the company went bankrupt and piled work on me, they went down and they wanted someone to fix it, that someone was me. It was the worst. And then when



started, they changed the study, from 'Game Design' to 'Communication and Multimedia development, Major: Game Design'. Everyone wanted to get out of the study, we didn't learn what we were supposed to and suffered from it. We started with over 200 students and in the end 20 of them graduated. One of them was me though, I just wanted to be done with it so I succeeded. I had a bad grade but I finished and my teacher congratulated me saying: "Go, celebrate your freedom!".

7. Do you ever feel judged by people around you because of your autism?
- If so, how much do the people that judge you know about autism?

P:
Good question… I don't think I ever felt judged personally, but from the media, yes. And also from the psychoeducation course I mentioned earlier. The media and the course portraits Autism so generalized, in such a stereotypical way. It says: "This is what autism is like, this is what you suffer from." And I am like: "No, I don't. I don't relate to it!".

They told me in the course to go to school and tell them that I have autism but I don't want to! I did not trust anyone. I know someone, he would get psychotic when under stress, and when he disclosed himself he was not helped at all, he was discriminated against and it ended really bad for him, he had to do an extra year of studying just because they thought he wasn't able to do it even though he was. In the end I was a witness for him when he filed a complaint against his school. So I don't believe that disclosure helps, I think it makes things worse.

8. How does judgement by others make you feel about yourself?

P:
I go into a defense mode, because I don't accept what the media (or the course) makes autism look like for myself. I get frustrated and annoyed with the media because they take the typical picture of a little boy staring into a snow globe and say that is what autism is like. The truth is that there are so many people falling into the category of autism and they can't be generalized to the picture the media portrays. Autism is a spectrum and I for myself only recognize not liking touch, eye contact and big crowds, the rest doesn't apply. So I stopped watching the media, they want it (ASD) to look like a spectacle so I just don't watch it anymore.

I:
How do these stereotypes in the media make you feel about yourself?

P:
They don't make me feel bad about myself because I know that they are not true and that the way they make it look is not who I am. I do sometimes get annoyed though. And sometimes I worry

about relationships because I would like to have one on one point but it will be difficult because of not liking to be touched.

9. How do you deal with the diagnosis when you meet new people?
- do you tell them about it?
- what do you tell them?
- How does it make you feel to tell people about your diagnosis?

Things I tell them right away	Things I tell them over time (in order of appearance)

P:
I never tell anyone about my ASD diagnosis, I don't feel like I have it so why would I say it?

With DCD I did tell people around me, but usually I just told them that I have issues with eye contact, touch and big crowds. That was never an issue for anyone. Sometimes people would guess that I have a diagnosis and then I admit it but 9 out of 10 don't.

I had a teacher once who was talking about traits of ASD and then said: "I should know what that means, since I have a diagnosis myself.". I didn't expect that so it just shows that the diagnosis is also applied to people that don't have all the symptoms and that don't appear like they have ASD at all.

After the ASD diagnosis I stopped telling people about DCD too. But in my first study I disclosed the DCD diagnosis to my mentor because I wasn't doing well, I had too little ECTS and wouldn't make eye contact with people. So I told him that DCD is the reason. He said that people who have this cannot become teachers and really talked me down. Then he took me to the dean and they both made me feel like I could never become a teacher and made me quit my studies. All the *time I was thinking "this can't be happening, is this really happening?", even on the train home it felt like an alternate reality.*

Years later, when I got help after the ASD diagnosis, they told me that what happened there is not formal policy, it was discrimination and I should've fought it. Maybe I should have but back then I was too low mentally to fight against it.

I:
That is a very negative disclosure experience. Did you have positive experiences with disclosure, too?

P:
Yes, up until that point people I disclosed myself to were really supportive, also the teachers. And I definitely need the support. So considering the pro's and con's, there are more benefits to me having a diagnosis because it allows me to get the support I need.

10. Do you think telling people about your diagnosis changes the way they think about you and treat you?

Positive change	Negative change

P:
I don't disclose my Autism, with DCD people were supportive when I told them.

But with Autism, I don't think it helps. People only listen to the media and the stereotype of Autism shown there. They would think "Oh, no let's help that person." but then treat you like a child. I had a friend who disclosed her ASD in school and that is what happened to her; she was treated like a kid. She was okay with it but I am not. Because of the stereotypes in the public media I think it is better not to disclose ASD because it would change people's attitudes in a negative, stigmatizing way. It is difficult to change the mainstream image of ASD so it is better if people don't know otherwise they will apply those stereotypes to you.

There are only 3 things you need to know about me, and those are not the diagnosis ASD but the symptoms I told you about. They are part of me, ASD is not.

11. How would you describe the way you cope with your autism for yourself?
- What are challenges for you and how do you deal with them?
- What aspects of your autism do you think you deal well with?

I:
The first question doesn't really apply to you because you don't identify with Autism, but could you answer the question about what challenges are posed on you due to the symptoms you think describe you?

P:
Challenges are that I don't really enjoy going out, I am not able to be in big crowds. That really hampers me.

And when I wanted to do my drivers license, they gave me a form with a checklist of issues or symptoms applying to me, one of them was 'brain damage'. And I thought that doesn't apply to me, so I didn't put a cross. But then they found out about my ASD diagnosis and said they consider ASD as brain damage so I couldn't do my drivers license. That was bad. I don't think my brain is damaged, maybe some connections are different, but it is not damaged!

I:
You said in the beginning that you do meet people and that you go to gaming events as well sometimes. So even though going out into big groups is a challenge for you, you do it. Is that right? How do you deal with the discomfort then?

P:
I focus on the common interests that I have with people, or I focus on the game or my conversation partner so much that I don't notice the crowd anymore. I also learned a breathing exercise which I do before I enter those situations and that really helps.

Having a relationship on one point worries me sometimes, because I would really like to have one, but it will be difficult because of my issue with touch. And sometimes people would tap me on the back and I immediately notice it, I don't say anything but I deal with it in my head for the next half an hour.

I do want to go out there and live my life though, so I enter challenging situations and try to deal with them nonetheless. No one seems to notice the eye-contact issue too much, so it doesn't bother me. It also seems to get better, as a child I never made eye contact with anyone. Now I subconsciously try to do it more often and I think it works. I also barely get the feeling of choking in crowds anymore, but I do get tired from it quickly. I can take touch now, under some very particular circumstances that I don't want to talk about further.

12. What advice would you give someone who just received their diagnosis?
- Which type of treatments did you receive?
- Which one(s) would you recommend to others and why?

I:
Did you follow any treatment that you would recommend to other people with an ASD diagnosis?

P:
Not really…? Individual therapy really helped me when I got bad mentally. My counsellor told me to do it and it helped me calm down. I am in a more comfortable mind space now. I do 2 different kinds of individual therapy which I don't want to disclose. I don't think treatment can be generalized, the treatment that I am doing can only be recommended to people that have the same issues that I have.

What advice I would give is difficult, too. It really depends on the previous history of the person and the age of diagnosis. I received my ASD diagnosis a lot later than most people so I don't think I can give general advice.

The only advice that I can give is that breathing techniques can help calming you down. And when you feel uncomfortable in crowds, focus on something else that you like, that you are interested in, for me that would be board games. That works for me, but it might not work for others.

I had a class-mate that I saw semi-regularly. When I saw her on one point I could really tell just by her eyes that she wasn't doing well mentally. So I got to talk to her in a quiet moment when it was only her and me and I talked to her. After a while she told me herself that she wasn't doing well and I advised her to go to ATN, told her that the waiting lists are long but that here she would get the help that she needs. "STUMAS" dropped her from what I felt like, they were supposed to help her but I was the only one who noticed she was struggling. I think they fell short on helping her but I can't tell for sure either. I felt like they could have prevented her from feeling so bad and dropping out of her internship.

Advice only works on a very personal level though, there is so much history to a person that needs to be considered. I think one of the biggest issues is that there is still such a big taboo around mental issues, no one talks about it. I think that needs to change, people need to talk about their mental struggle more. I also still struggle talking about it all very openly, my therapist literally needs to pull it out of me.

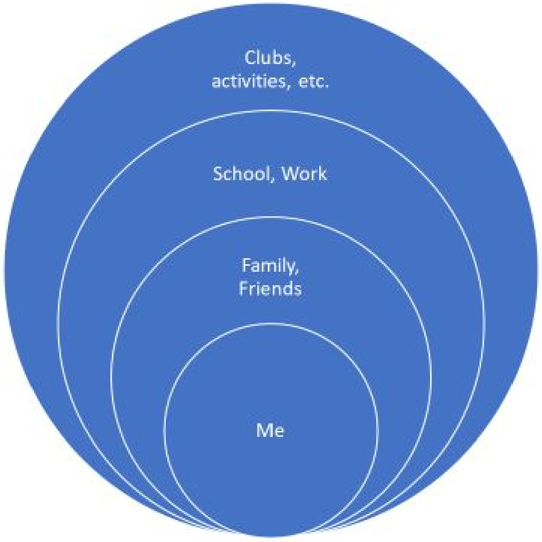
Appendix 3

Interview Transcript Participant 2

Interview Participant 2
27.05.2020

Note:
Questions asked verbally are indicated by ***bold*** *letters. The original interview structure served as a guideline to cover the topics of importance, indicated by stating the original questions above the sections relating to them. Questions asked by me are indicated by* ***I:,*** *whereas questions asked by my supervisor are indicated as* ***K:*** *and responses from the participant are noted as P:. (...) indicates chats that were not related to the interview.*

1. Who are the people around you?



I:
The first question is to get a sense of your social environment. So if you could explain, maybe with the help of the graphic, who the people are that surround you in your usual daily life?

P:
Sure. I currently still live at home. So I have my mother and my father, they are both teachers in middle education. My dad is an MBO teacher and my mom is a grade 3 teacher. And I live with my brother, he is 2 years younger than me, so he is 22 now. He also has autism. And I have my sister but she lives in her own room in the city. She is 20.

So those are the people I am with mostly. I also have my grandparents who live a few streets away from my house and also the extended family, like aunts and uncles. I see them quite regularly. I do groceries for them once a week now in Corona times. I am also helping them with their computer, which they just bought.

I:
Do you generally have good relationships within your family?

P:
Yes. We're close and they are understanding, they also know my brothers and my diagnoses. It's generally well understood in the family and it gives a certain freedom for when we're away with the family in a large group for a weekend, that sometimes I am not joining activities because I need some time alone. So that's very nice.

I:
What about clubs, or other social activities?

P:
I just finished school, I have a bachelors degree now in computer science. And I am currently working at the place at which I did my final internship in the last half year. I am still there but I am looking for something else because I am not really happy with how it is going there.
But I have a really nice colleague who is the same age as me and my boss who is 30 / 35. I generally have good relationships with them but I don't see them outside work often. Sometimes I play a game with my colleagues but that's it. We're a really small team.
I used to do sports with people but I can't now. I used to be in a swim club until 5 years ago, with my nieces, so it was a family thing as well.
This is also the reason why I joined the social skills training (here at ATN) because I want to do more outside of my family. But I haven't been able to practice it a lot now because of Corona.
But I have friends with whom I'm gaming, from Norway, from Serbia, they are all over the world.

2. When did you get diagnosed with Autism spectrum disorder?
- how old were you?
- how did you get in contact with a psychologist?

______________________X____
_

Time >

I:

Okay the second question is about the process of getting a diagnosis. So how old were you and how did you get in contact with a psychologist?

P:

I was 10/12 when I got the diagnosis. I was at the same primary school that my mom worked in. And when I was in the 5th grade, we moved to another building in the same village because the school was under construction. And apparently that caused some issues for me.
I talked to my mom before about this, because my memory is not that great anymore. So I did some tests at school because I got panic attacks and did not want to go to school anymore. That is one of the reasons why we went to another autism center (for children). And there I got a proper diagnosis, I got some training and my parents got group therapy with other parents of children with autism.
And since then I've been to mental health institutions every year for some kind of reason.

3. How did you perceive the diagnosis and the information you were given in the process?
- what did the psychologist tell you, how much detail did he give you?
- did you feel like you were described well?

I:

Do you remember the diagnostic process itself and the information they gave you?

P:

Not exactly, I remember doing IQ tests and personality tests and being with people observing me while I interacted with things they wanted me to.

K:

Did they let you play with toys?

P:

I don't really remember but I think so, I think that would've been the way it went.

I:

Do you remember how and when you really understood that you were given an autism diagnosis?

P:

I realized I was having troubles, so the older I got the more I became more conscious of why that was happening. That was probably somewhere around high school, when I mostly connected the dots. And now that I am getting older I notice more about what I can and can not do, what is good and bad for me etc. Holidays have always been a drag for me so I am not going on holidays anymore because they cost more energy than they give.

K:
What about the word autism, did they explain to you what it meant?

P:
No, I don't really think they did.
I think I kind of grew into it. It was not a clear line for me. I imagine someone getting a cancer diagnosis and being shocked. It was not like that for me. The more I understood about it, the more I felt like it was just something I had.

4. How did you feel about yourself / perceive yourself before the diagnosis?
- did you have a feeling you were different from other people?
- if so, what did you feel was different?

__________________<____X____
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Time >

I:
Do you remember how you perceived yourself before the diagnosis? Do you remeber if you ever felt different from other kids?

P:
Yes I think so. Especially looking back, when I was young I think I didn't have many friends and I didn't like to go to sleep overs, or playdates or parties later in high school. So I think that was a clear indication that there was something going on, and then I also had panic attacks and intense anxiety.
(...)
It was a mixture of things, the autism, the anxiety. So I have an autism diagnosis but also a generalized anxiety disorder diagnosis. I think I was never comfortable in school, I had stomach aches in the mornings, that I remember really clearly. I didn't like "Sintaklaas" because of the surprises. I once got a "dirty" present and had such a bad panic attack that I went into my

mothers class, who was watching a movie with their students and I sat there for the rest of the day because I had so much fear that was all I could do.
That is all I can remember. I don't think there was a difference between before and after the diagnosis though. The diagnosis was not a clear line because no one said to me 'you have autism'. Maybe that would've been nice early on. But over time I started to understand what it means.

5. How did you feel about yourself afterwards?
- did you see yourself differently afterwards?
- did you struggle against the diagnosis?
- did you accept it?
- did you see positive / negative aspects of it?

______________________*X*____*>*_________________*>*_______________*>*______________
___

Time >

6. Do you think having autism is part of who you are?
- if so, would you call it a central aspect of yourself?

K:
So it is a thing you have, but do you feel like it is a part of you, of your identity, or just a part of who you are?

P:
I am not really sure. I think it is a part of me and I know how to live with certain things coming with it. And I know it prohibits me to do certain things. At a certain point you learn that some things are better for you than other things. I don't know, it's just my life. And it is a big part of my life but I don't say: "I am Joris, I have Autism." It's not something I write down on my ID card.

K:
Your brother also has the diagnosis and you met people in the group that also do and everyone has the same label but everyone is a bit different. Does that confuse you?

P:
I know that autism is a spectrum and it is really wide, a lot of different problems have the same label. I am not really socially awkward for example but my brother is. He doesn't talk about his feelings, I probably do it too much. I know that people have different forms of it.
I think I can pick it out more easily, when I see people having social problems, sitting weirdly or not knowing how to respond or behave, I know how to respond to people like that.
The american show "The Good Doctor" is a good example. The doctor is really smart and socially awkward, he is also autistic. And there are some parts of the show that I can relate to really well and then there are others that are very extreme and I don't relate to.

(...)

I:
So you say autism is a spectrum and some parts you relate to and those you also see as part of yourself?

P:
Yes.

I:
Which traits do you recognize in yourself and which do you not but have maybe seen in other people with the diagnosis?

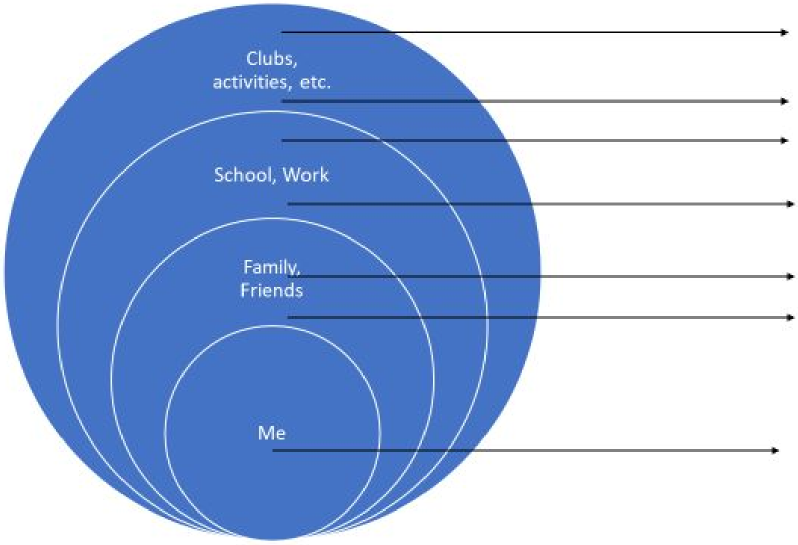
P:
One of the things I learned to do more is to look at people while I am talking. It feels really unnatural to do it but I learned it by talking a lot and being in school. I became really aware of it and people like it when you look at them while you talk. So I learned it and practiced it and I became better at it. It still feels uncomfortable. I think that is a typical difficulty for people with autism. The fear part was also really big for me. So a lot of training was around the fear, Cognitive behavioural Therapy. I've done a lot of that. The fear became more of a focus than autism on one point.

K:
Going back to "The Good Doctor" and displaying autism in the media. How do you feel about that?

P:
It is something I still struggle with because people don't understand what it really means, they don't understand that autism is so different for everyone. They have a stereotypical perception of

it. Some time ago there was a video on youtube of a kid and you saw what he sees, strong lights and intense colours. It is something I also experience, maybe not on that level though.
It is really difficult. I have a job interview today. Usually I wait until the end to tell them that there are some things that I would need in order to work better. But if you drop the word autism, how are people going to react, what is their image of it? That is really difficult because you can explain to them what it is but sometimes they just don't know that it is different for everyone.

7. Do you ever feel judged by people around you because of your autism?
- If so, how much do the people that judge you know about autism?



I:

Do you think there is more judgement from people that know less about the autism spectrum?

P:
Yes I think so because of movies and tv shows that show it in a certain, very extreme way. I assume that the image people have of autism is influenced by that. So I think they judge more if they only know that image but the more they know the more they can see that we are all the same - we are all people. And everyone has some loose wires.
I think media portraits have become more in the last couple of years, also there is more education in schools. I am kind of sad that that didn't exist when I was younger, it would have helped. So yes, I think the less they know the more judgemental they are.

I:

Did you have moments or experiences in which you felt judged or stigmatized because of your autism?

P:

I don't think that really happened to me in an extreme way. It is usually more the case that if I react a certain way and it can be explained with my autism, I explain it. So I haven't been discriminated against because of my autism.

My field of study is also a very good environment for people with autism.

There are a lot of people with autism in computer science and those people sometimes even do better. So there is a lot of appreciation for autism I think because it is known what these people do for the field / the company. So I think for my computer science it is maybe even a plus to have autism.

I:

What are the positive, beneficial aspects of autism for computer science?

P:

Detail orientation. A part of programming is that mistakes are preventable or to catch mistakes in your code to run it. That is a part of logic and it is something I can generally do really well so I do see it as a benefit. Being focussed on doing your job and wanting to do it well, and thinking abstractly really helps as well when programming. And those are positive aspects of autism.

What I need is a quiet place. So I don't like public offices with a lot of desks in one room, I would go mad. I can't focus that well with people around me. Even though at work I have sound-blocking headphones I can still hear that people around me are doing something, walking around, hearing the street, seeing flashes of light. One of the first things I noticed first when I came in here is the really bright, colourful carpet. All of the lines on it make me see a blur because the lines are too busy to let me focus on them.

So I am easily visually stimulated. I am also intrinsically stimulated a lot. I can constantly feel everything in my body, I am always aware of my heart beat and I can feel stomach pain easily, I can not really get my attention away from it because it is so present. The feeling screams really loud in my mind and it makes it difficult to focus. That in combination with hypochondria is really intense for me.

But if I can focus on one thing and I am sheltered enough from outside noises I can focus really well and do a lot of work. I need to have the conditions to deal with it though.

(...)

K:

So in a job interview, you wait until the last bit until you tell about your autism, do you do it because you feel obliged to or because you want to?

P:

That is something I really struggle with still. Should I tell them? Am I obliged to tell them that in order to be fair? Because it can be helpful but it is also baggage for them, because my manager needs to provide me with circumstances in order for me to work as well as other people without them. So it is a balance. So if I already feel that the other person is inclined to understand it, then I am comfortable to tell them. So sometimes I tell them up front, sometimes I wait until the end.

For my coming job interview, I already told the recruiter, but not the manager that I will have the actual interview with. So they know at a certain level. I also did a personality test, which they could conclude it from. Most of the time, when I am not hired, it is because I wouldn't be a good fit in the team. Sometimes I think it is a reason to be denied a job. I never asked directly though.

8. How does judgement by others make you feel about yourself?

I:

Can we go back to the media presentation quickly? If you read or see content about autism, what does that do to yourself?

P:

There are some negative aspects about autism. But in the media they don't show the really bad stuff, the panic attacks for example. I don't know if people want to be confronted with that if they don't suffer from it. It is really horrible if you have it yourself and for people around you that need to cope with it. But usually you don't want to share it because it might trigger other people as well. So you need to be careful if you share triggering content online.

So I don't know how to best and realistically portrait the negative aspects.

On the news usually autism is not talked about, unless there is an extraordinary success story of someone with autism. I don't feel stigmatized by the media because I am really self-aware, I know what works for me and what doesn't and I learned to talk openly to people around me and ask for what I need. I learned that that is the best way to cope with it. So I don't feel stigmatized. It makes me feel good about myself. But for example, my brother is not able to do this and talk openly about it, so it is not how it works for him. For me it is good and I know how to help myself but for other people it is more difficult.

9. How do you deal with the diagnosis when you meet new people?

- do you tell them about it?
- what do you tell them?
- How does it make you feel to tell people about your diagnosis?

Things I tell them right away	*Things I tell them over time (in order of appearance)*

I:

About the disclosure, could you go into detail about what you disclose and in which situations and what you do not disclose to people?

P:

I usually stick to the most general things that people know about autism. For the work environment, I talk about the intensity of stimuli.

When there are a lot of colours and lights and people it can make me feel really tired because I have trouble regulating it. It takes me a lot of energy sometimes to do things that are normal for others. I try to explain it accordingly, so people get a sense for how I work. I tell them what applies to me and what I need in my environment. I don't drop my autism out of thin air but in the context of what I need. But then I do tell them, in a practical context. I've never been asked directly.

I:

Do your friends that you game with know about the diagnosis?

P:

I think some of them know. I have a friend from Serbia. I suspect that he might also have some kind of autism. We talk about certain things in life, he is older than me and has about the same job as I do so I can also talk to him about my job. And he is really supportive in steps that I am

taking which is really nice. And when I struggle he has some advice, so that is really cool. Other friends don't really know and also don't really care because it does not matter, we are gaming to have fun and not to be productive members of society.
Autism matters more when people expect things from you, if they want something from me and it does not go the way they want it to. When those issues are related to autism I can explain it to them in that way, that there are certain things about me that should be taken into account.
I learned that with experience.

10. Do you think telling people about your diagnosis changes the way they think about you and treat you?

Positive change	*Negative change*

11. How would you describe the way you cope with your autism for yourself?
- What are challenges for you and how do you deal with them?
- What aspects of your autism do you think you deal well with?

12. What advice would you give someone who just received their diagnosis?
- Which type of treatments did you receive?
- Which one(s) would you recommend to others and why?

K:
Are there strategies that you help yourself with, which could also help other people with difficulties?

P:
There are a few things. I really like to just be home for a day for example. I work 4 days a week, I am free on Wednesdays. Which is good for me because it cuts the week in half. I have the day

for myself, to sleep in, to recharge, to do things I want to do. It helps to take time, to take it easy. I think a lot of people don't take enough time for themselves, they are always running and doing stuff and that is really exhausting.
So I really enjoy having that day off in the week and it is something I will be asking for in my job interview (later in the afternoon) as well, because I really want to keep it this way. It works well for me. And also for them, when I feel better I do a better job. Some people see it that way, some people don't and are more stuck in the old ways of working. Working 9-5, putting the specific hours into work.

I had an issue with my boss last week because my breaks were getting too long. I went home to eat and then took a walk afterwards and he didn't like that, he does have an old way of thinking about business. I think if I do the work we discussed I should do and I make sure I keep myself happy, what does he care? So that is one reason why I am thinking about switching my job.
To get back to the question; time off is really important to me. And to make sure that things which require a lot of energy for me, like driving a car, are well planned. I need to make sure to get enough rest. I need to know what I can do and can not do and plan it.

I:
What are some of the challenges for you?

P:
Driving, loud noise. Intense visual stimuli, like too many colours and patterns. If that happens I sometimes take my glasses off to reduce stimuli.

I:
What other mechanisms do you have to cope with challenges?

P:
I wear headphones sometimes. And I am really mindful about what I am doing and avoid situations that are too much for me.

K:
Did you find these strategies out yourself or did you also learn from other people?

P:
I think most of them I experienced myself. And I believe that is also the only way to do it. To just experience on an energy level what is good for you and what is too much. And when you step over a boundary you notice it afterwards and then reflect on what was too much and learn from it.

K:
What are your sources of support?

P:
Mindfulness meditation really helps to quieten down your thoughts and change your way of thinking.
I am using an app, I don't remember how I found out about it, maybe I found it myself, maybe someone recommended it to me.
I talk to my parents or my friends about issues, I like to talk to my therapist here as well because it adds another layer of reflection and insights. I am doing PMT therapy now (Psychomotor therapy), it helps me to understand what I am feeling in my body because I am usually feeling a lot and I can overfocus on that. My mind then jumps to the conclusion that I am probably sick. So PMT helps to understand what I am feeling.
CBT helped me a lot for my anxiety and I am still keeping the mechanisms that I learned there.
Social skills training helped me as well but I could not practice it a lot now because of Corona.

I:
To conclude; you said that you grew into autism. Would you by now say that the category autism is part of your identity?

P:
I would say it is a big part of my life. Yes, I think it is a part of my identity. The parts of autism that I recognize in myself are definitely part of who I am.
Now, if I run into some kind of issues with other people I am wondering; is it my autism, is it who I am, is it medicine that I take? So sometimes I get a little bit confused.

I:
Here you say; is it me or is it autism? Which sounds like they are not the same.

P:
I think I mean more; is it explainable through it. That is a better way to put it. Autism is a part of me, but is the behaviour from the part that is 'autistic'. Parts of myself I can recognize in the category of what autism is, so the way I think about it is that it explains parts of myself.
The difficulty is that there are so many different expressions of it but it is all called autism.

Appendix 4

Category code book

Category code	Definition of Categories	Anchor examples	Coding rules
C1 Acceptance	Acceptance of the ASD diagnosis as being part of one's identity, of recognizing oneself within the diagnostic details, agreeing with the diagnosis.	*"See, I was satisfied with my "DCD" diagnosis."*	
C2 No Acceptance	Not accepting the diagnosis of ASD as being part of oneself / describing oneself accurately. Not recognizing oneself as belonging to the category of people with Autism Spectrum disorder.	*"I do "fight" with the ASD diagnosis in the sense of I don't accept it."*	
C3 Continuity	Having a consistent sense of self across time and situation, in specific across time before and after the diagnosis but also across other life events.	*"I did feel different from others, that's why I got the diagnosis (DCD)."*	
C4 Disruption	Relating to a disruption of one's life and self-concept by a life event, including but not limited to the event of	*"But then the diagnosis they gave me, that fit me, doesn't exist anymore because of money?"*	

	being diagnosed.		
C5 Self-efficacy	The subjective perception of oneself as being in control of oneself and one's life. This includes feeling able to face challenges, achieving goals and succeeding at tasks.	*"I do want to go out there and live my life though, so I enter challenging situations and try to deal with them nonetheless."*	Self-efficacy overlaps with self-esteem in multiple cases *"I do want to go out there and live my life though, so I enter challenging situations and try to deal with them nonetheless."* - Is coded as self-efficacy as an indicator of feeling able to face challenges
C6 Lack of self-efficacy	Feeling a lack of autonomy, a lack of ability to succeed in tasks and goals and hopelessness in regard to challenges.	*"...I was too low mentally to fight against it."*	
C7 Self-esteem	The feeling of an intrinsic personal sense of worth, self-respect and pride, including possessing good qualities and deserving a happy life.	*"They don't make me feel bad about myself because I know that they (the stereotypes) are not true and that the way they make it look is not who I am."*	Self-esteem overlaps with self-efficacy in multiple cases *"It makes me feel good about myself."* - Is coded as self-esteem as indicating a sense of one's own worth
C8 Lack of Self-esteem	The negative evaluation of oneself including diminished sense of self-worth, feelings of shame and focussing on negatively evaluated characteristics when	*"...,he made me feel like I was not good enough,..."*	

	describing oneself.		
C9 Social Stigma	Negative attitudes of the social environment towards the individual due to their category. This includes stereotyping.	*"The media and the course portraits Autism in such a stereotypical way. It says: "That is what Autism is like, this is what you suffer from."*	
C10 Social Support	Positive attitudes by the social environment of the individual, including understanding, openness and respect as well as practical and emotional support. This category includes professional support (e.g. therapy, counselling etc.)	*"She (the counsellor) was really great though. She helped me a lot, also with studying, I actually miss her."*	
C11 Lack of Social Support	The absence of positive attitudes by the social environment towards the participant. Specifically the unwillingness to understand and help the participant in emotional or practical ways.	*"I contacted so many companies myself and no one helped me, the phone was never answered."*	
C12 Internalized Stigma	Adopting the negative attitudes of society towards oneself, including social withdrawal, alienation, stereotype endorsement and identification with	Not applicable	

	negative social attitudes.		
C13 Disclosure	Act of telling other people openly about one's diagnosis	*"But in my first study I disclosed the DCD diagnosis to my mentor because I wasn't doing well, I had too little ECTS and wouldn't make eye-contact with people. So I told him that DCD is the reason."*	
C14 No Disclosure	Not telling other people openly about one's diagnosis	*"I don't disclose my Autism."*	
C15 Psychoeducation	Detailed information about an ASD diagnosis available to the general public, the social environment or an individual.	*"I had psychoeducation about it and they showed us slides with symptoms, about what ASD is."*	
C16 Lack of Psychoeducation	Lack of knowledge and information about an ASD diagnosis in the general public, the social environment or an individual	*"...so they did a brief test, like 30 minutes, and then said: "Yeah, you got it (ASD)."*	
C17 *Discrimination*	Unjust treatment of a person of a specific category	*"So I told him that DCD is the reason. He said that people who have this cannot become teachers and really talked me down…"*	
C18	behavioural or mental	*"...when I did my*	

Bad mental state	patterns of the participant that are indicated to cause significant suffering and/or impairment of social functioning	*teacher study ("LVO"), I was 21/22, my mental state went bad and I had to quit because it was too taxing."*	
C19 *Concerns*	Anxieties or worries of the individual related to their personal or occupational life	*"Having a relationship at one point really worries me."*	
C20 *Coping methods*	Strategies of the individual to manage challenges effectively	*"The only advice that I can give is that breathing techniques can help calming you down."*	
C21 *DCD diagnosis*	Mentioning the diagnosis category of Developmental Coordination Disorder	*"..., with DCD people were supportive when I told them."*	
C22 *ASD diagnosis*	Mentioning the diagnostic category of Autism Spectrum Disorder	*"...we went to another autism center (for children). And there I got a proper diagnosis,..."*	
C23 *Receiving diagnosis*	Mentioning the point in time of reception of one's diagnosis	*"I showed some signs at a very young age, so my mother took me to a psychologist, I guess she was worried because I wasn't like the other kids. I received a DCD diagnosis…"*	

C24 *GAD diagnosis*	Mentioning the diagnostic category of generalized anxiety disorder	*"... but also a generalized anxiety disorder diagnosis."*	

Appendix 5

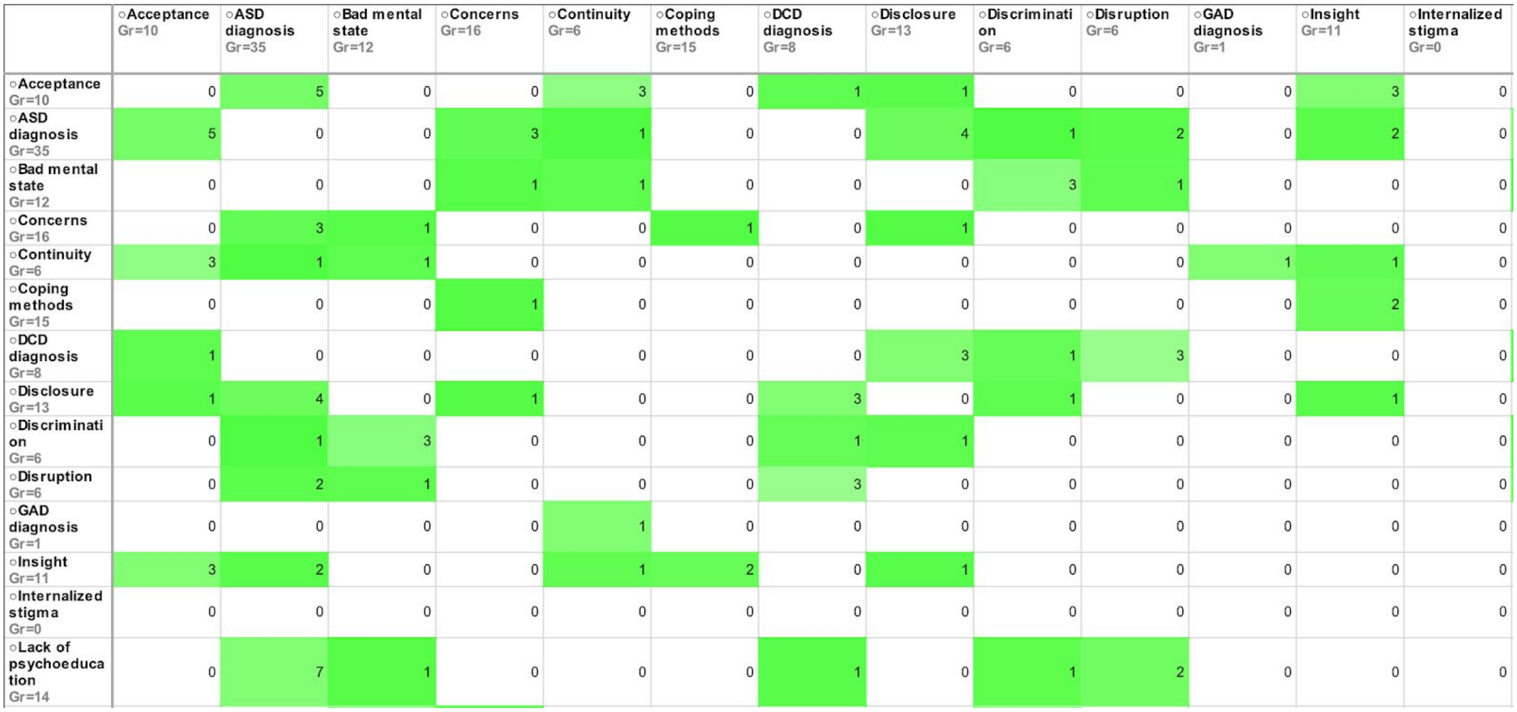
Code count table

	Interview Participant 1 (1).pdf Gr=127	**final interview participant 2 (2).pdf** Gr=108	Totals
○ **Acceptance** Gr=10	2	8	10
○ **ASD diagnosis** Gr=35	15	20	35
○ **Bad mental state** Gr=12	9	3	12
○ **Concerns** Gr=16	5	11	16
○ **Continuity** Gr=6	2	4	6
○ **Coping methods** Gr=15	7	8	15
○ **DCD diagnosis** Gr=8	8	0	8
○ **Disclosure** Gr=13	5	8	13
○ **Discrimination** Gr=6	6	0	6
○ **Disruption** Gr=6	4	2	6
○ **GAD diagnosis** Gr=1	0	1	1
○ **Insight** Gr=11	3	8	11
○ **Internalized stigma** Gr=0	0	0	0
○ **Lack of psychoeducation** Gr=14	9	5	14
○ **Lack of self-efficacy** Gr=7	7	0	7
○ **Lack of self-esteem** Gr=4	4	0	4
○ **Lack of social support** Gr=4	4	0	4

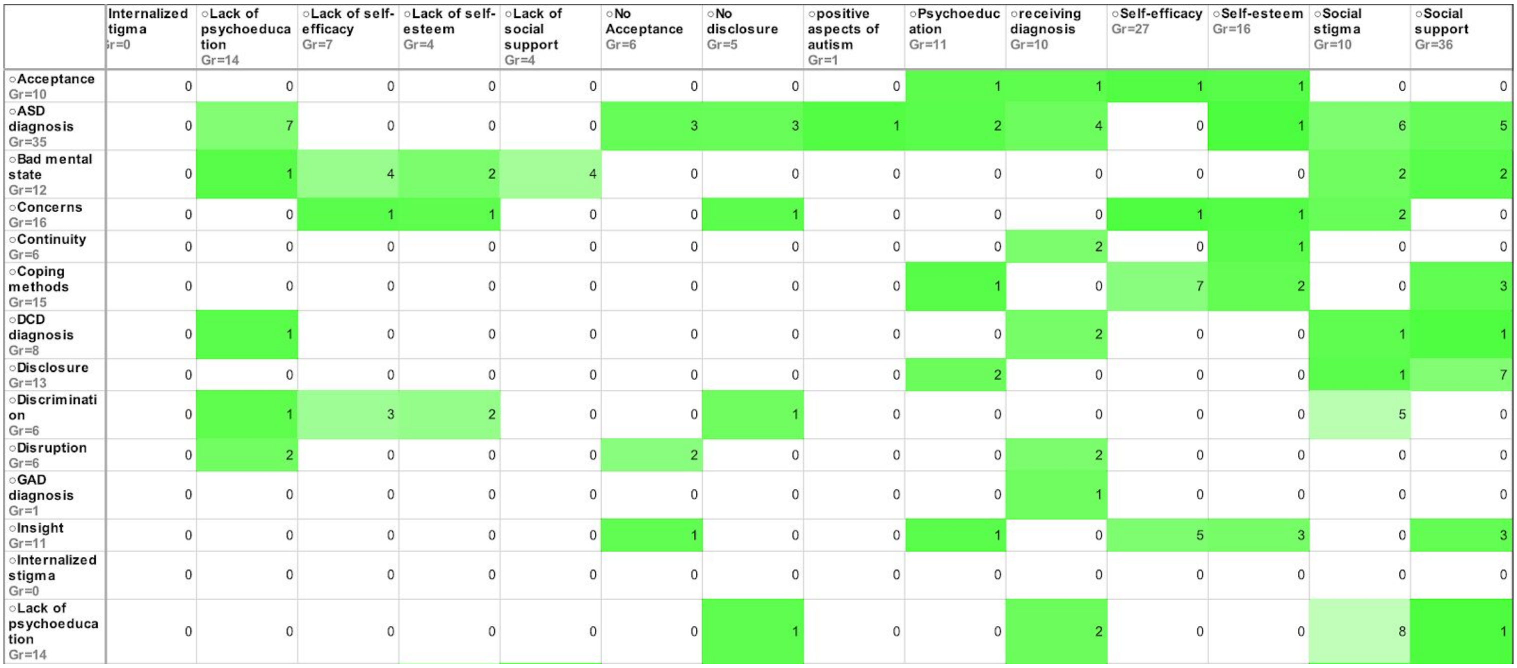
○ No Acceptance **Gr=6**	6	0	6
○ No disclosure **Gr=5**	5	0	5
○ positive aspects of autism **Gr=1**	0	1	1
○ Psychoeducation **Gr=11**	4	7	11
○ receiving diagnosis **Gr=10**	7	3	10
○ Self-efficacy **Gr=27**	13	14	27
○ Self-esteem **Gr=16**	9	7	16
○ Social stigma **Gr=10**	6	4	10
○ Social support **Gr=36**	18	18	36
challenges & coping **Gr=31; GS=2**	12	19	31
negative impact **Gr=54; GS=10**	43	11	54
neutral **Gr=66; GS=5**	37	29	66
positive impact **Gr=92; GS=6**	43	49	92
Totals	293	240	533

Appendix 6

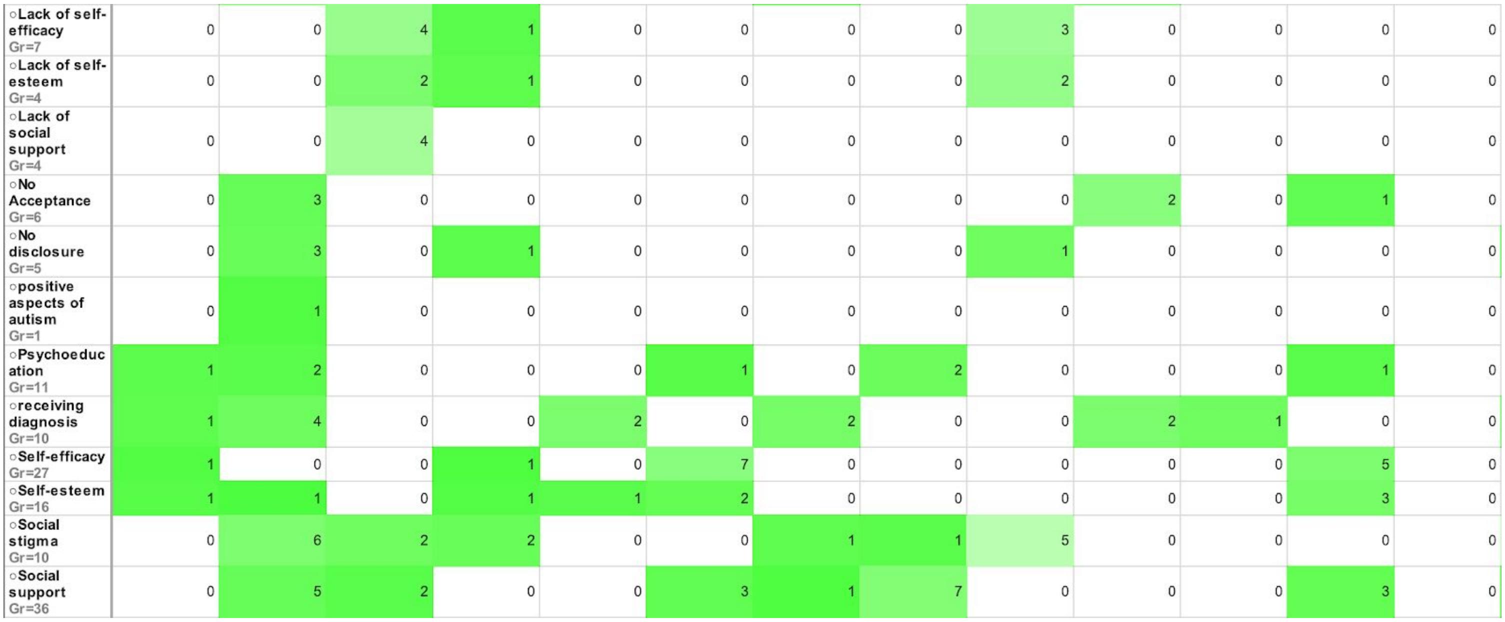
Code co-occurrence table



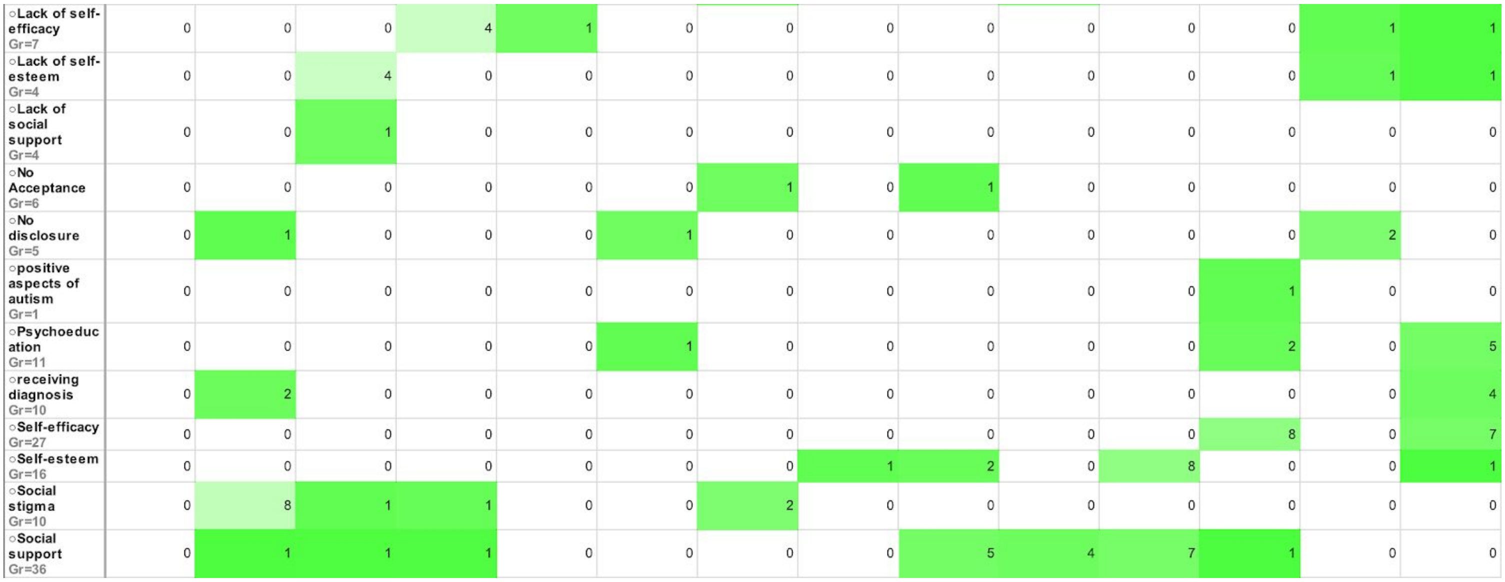
	○Acceptance Gr=10	○ASD diagnosis Gr=35	○Bad mental state Gr=12	○Concerns Gr=16	○Continuity Gr=6	○Coping methods Gr=15	○DCD diagnosis Gr=8	○Disclosure Gr=13	○Discrimination Gr=6	○Disruption Gr=6	○GAD diagnosis Gr=1	○Insight Gr=11	○Internalized stigma Gr=0
○Acceptance Gr=10	0	5	0	0	3	0	1	1	0	0	0	3	0
○ASD diagnosis Gr=35	5	0	0	3	1	0	0	4	1	2	0	2	0
○Bad mental state Gr=12	0	0	0	1	1	0	0	0	3	1	0	0	0
○Concerns Gr=16	0	3	1	0	0	1	0	1	0	0	0	0	0
○Continuity Gr=6	3	1	1	0	0	0	0	0	0	0	1	1	0
○Coping methods Gr=15	0	0	0	1	0	0	0	0	0	0	0	2	0
○DCD diagnosis Gr=8	1	0	0	0	0	0	0	3	1	3	0	0	0
○Disclosure Gr=13	1	4	0	1	0	0	3	0	1	0	0	1	0
○Discrimination Gr=6	0	1	3	0	0	0	1	1	0	0	0	0	0
○Disruption Gr=6	0	2	1	0	0	0	3	0	0	0	0	0	0
○GAD diagnosis Gr=1	0	0	0	0	1	0	0	0	0	0	0	0	0
○Insight Gr=11	3	2	0	0	1	2	0	1	0	0	0	0	0
○Internalized stigma Gr=0	0	0	0	0	0	0	0	0	0	0	0	0	0
○Lack of psychoeducation Gr=14	0	7	1	0	0	0	1	0	1	2	0	0	0



	Internalized tigma r=0	○Lack of psychoeducation Gr=14	○Lack of self-efficacy Gr=7	○Lack of self-esteem Gr=4	○Lack of social support Gr=4	○No Acceptance Gr=6	○No disclosure Gr=5	○positive aspects of autism Gr=1	○Psychoeducation Gr=11	○receiving diagnosis Gr=10	○Self-efficacy Gr=27	○Self-esteem Gr=16	○Social stigma Gr=10	○Social support Gr=36
○Acceptance Gr=10	0	0	0	0	0	0	0	0	1	1	1	1	0	0
○ASD diagnosis Gr=35	0	7	0	0	0	3	3	1	2	4	0	1	6	5
○Bad mental state Gr=12	0	1	4	2	4	0	0	0	0	0	0	0	2	2
○Concerns Gr=16	0	0	1	1	0	0	1	0	0	0	1	1	2	0
○Continuity Gr=6	0	0	0	0	0	0	0	0	0	2	0	1	0	0
○Coping methods Gr=15	0	0	0	0	0	0	0	0	1	0	7	2	0	3
○DCD diagnosis Gr=8	0	1	0	0	0	0	0	0	0	2	0	0	1	1
○Disclosure Gr=13	0	0	0	0	0	0	0	0	2	0	0	0	1	7
○Discrimination Gr=6	0	1	3	2	0	0	1	0	0	0	0	0	5	0
○Disruption Gr=6	0	2	0	0	0	2	0	0	0	2	0	0	0	0
○GAD diagnosis Gr=1	0	0	0	0	0	0	0	0	0	1	0	0	0	0
○Insight Gr=11	0	0	0	0	0	1	0	0	1	0	5	3	0	3
○Internalized stigma Gr=0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
○Lack of psychoeducation Gr=14	0	0	0	0	0	0	1	0	0	2	0	0	8	1



○Lack of self-efficacy Gr=7	0	0	4	1	0	0	0	0	3	0	0	0	0
○Lack of self-esteem Gr=4	0	0	2	1	0	0	0	0	2	0	0	0	0
○Lack of social support Gr=4	0	0	4	0	0	0	0	0	0	0	0	0	0
○No Acceptance Gr=6	0	3	0	0	0	0	0	0	0	2	0	1	0
○No disclosure Gr=5	0	3	0	1	0	0	0	0	1	0	0	0	0
○positive aspects of autism Gr=1	0	1	0	0	0	0	0	0	0	0	0	0	0
○Psychoeducation Gr=11	1	2	0	0	0	1	0	2	0	0	0	1	0
○receiving diagnosis Gr=10	1	4	0	0	2	0	2	0	0	2	1	0	0
○Self-efficacy Gr=27	1	0	0	1	0	7	0	0	0	0	0	5	0
○Self-esteem Gr=16	1	1	0	1	1	2	0	0	0	0	0	3	0
○Social stigma Gr=10	0	6	2	2	0	0	1	1	5	0	0	0	0
○Social support Gr=36	0	5	2	0	0	3	1	7	0	0	0	3	0



○Lack of self-efficacy Gr=7	0	0	0	4	1	0	0	0	0	0	0	0	1	1
○Lack of self-esteem Gr=4	0	0	4	0	0	0	0	0	0	0	0	0	1	1
○Lack of social support Gr=4	0	0	1	0	0	0	0	0	0	0	0	0	0	0
○No Acceptance Gr=6	0	0	0	0	0	0	1	0	1	0	0	0	0	0
○No disclosure Gr=5	0	1	0	0	0	1	0	0	0	0	0	0	2	0
○positive aspects of autism Gr=1	0	0	0	0	0	0	0	0	0	0	0	1	0	0
○Psychoeducation Gr=11	0	0	0	0	0	1	0	0	0	0	0	2	0	5
○receiving diagnosis Gr=10	0	2	0	0	0	0	0	0	0	0	0	0	0	4
○Self-efficacy Gr=27	0	0	0	0	0	0	0	0	0	0	0	8	0	7
○Self-esteem Gr=16	0	0	0	0	0	0	0	1	2	0	8	0	0	1
○Social stigma Gr=10	0	8	1	1	0	0	2	0	0	0	0	0	0	0
○Social support Gr=36	0	1	1	1	0	0	0	0	5	4	7	1	0	0

Appendix 7

Full coding report

ATLAS.ti Report

Thesis Interview (participant 1)

Codes grouped by Code groups

Report created by user on 5. Jun 2020

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challenges & coping

2 Codes:

- **Concerns**

16 Quotations:

1:64 And sometimes I worry about relationships because I would like to have one on one point but it will…

Content:

> And sometimes I worry about relationships because I would like to have one on one point but it will be difficult because of not liking to be touched.

1:102 Challenges are that I don't really enjoy going out, I am not able to be in big crowds. That really h…

Content:

> Challenges are that I don't really enjoy going out, I am not able to be in big crowds. That really hampers me.

1:108 Having a relationship on one point worries me sometimes, because I would really like to have one, bu…

Content:

> Having a relationship on one point worries me sometimes, because I would really like to have one, but it will be difficult because of my issue with touch. And sometimes people would tap me on the back and I immediately notice it, I don't say anything but I deal with it in my head for the next half an hour.

1:112 I also barely get the feeling of choking in crowds anymore, but I do get tired from it quickly.

Content:

> I also barely get the feeling of choking in crowds anymore, but I do get tired from it quickly.

1:124 I also still struggle talking about it all very openly, my therapist literally needs to pull it out…

Content:
> I also still struggle talking about it all very openly, my therapist literally needs to pull it out of me

3:39 The fear part was also really big for me.

Content:
> The fear part was also really big for me.

3:42 It is something I still struggle with

Content:
> It is something I still struggle with

3:43 It is really difficult. I have a job interview today. Usually I wait until the end to tell them that…

Content:
> It is really difficult. I have a job interview today. Usually I wait until the end to tell them that there are some things that I would need in order to work better. But if you drop the word autism, how are people going to react, what is their image of it?

3:59 What I need is a quiet place. So I don't like public offices with a lot of desks in one room, I woul…

Content:
> What I need is a quiet place. So I don't like public offices with a lot of desks in one room, I would go mad. I can't focus that well with people around me. Even though at work I have sound-blocking headphones I can still hear that people around me are doing something, walking around, hearing the street, seeing flashes of light. One of the first things I noticed first when I came in here is the really bright, colourful carpet. All of the lines on it make me see a blur because the lines are too busy to let me focus on them.
> So I am easily visually stimulated.

3:61 I am also intrinsically stimulated a lot. I can constantly feel everything in my body, I am always a…

Content:
> I am also intrinsically stimulated a lot. I can constantly feel everything in my body, I am always aware of my heart beat and I can feel stomach pain easily, I can not really get my attention away from it because it is so present. The feeling screams really loud in my mind and it makes it difficult to focus. That in combination with hypochondria is really intense for me.

3:65 That is something I really struggle with still. Should I tell them? Am I obliged to tell them that i…

Content:

> That is something I really struggle with still. Should I tell them? Am I obliged to tell them that in order to be fair?

3:68 Sometimes I think it is a reason to be denied a job

Content:

> Sometimes I think it is a reason to be denied a job

3:69 But in the media they don't show the really bad stuff, the panic attacks for example. I don't know i…

Content:

> But in the media they don't show the really bad stuff, the panic attacks for example. I don't know if people want to be confronted with that if they don't suffer from it. It is really horrible if you have it yourself and for people around you that need to cope with it. But usually you don't want to share it because it might trigger other people as well. So you need to be careful if you share triggering content online.

3:86 Driving, loud noise. Intense visual stimuli, like too many colours and patterns. If that happens I so…

Content:

> Driving, loud noise. Intense visual stimuli, like too many colours and patterns. If that happens I sometimes take my glasses off to reduce stimuli.

3:98 Now, if I run into some kind of issues with other people I am wondering; is it my autism, is it who…

Content:

> Now, if I run into some kind of issues with other people I am wondering; is it my autism, is it who I am, is it medicine that I take? So sometimes I get a little bit confused.

3:102 The difficulty is that there are so many different expressions of it but it is all called autism

Content:

> The difficulty is that there are so many different expressions of it but it is all called autism

○ Coping methods

15 Quotations:

1:12 I don't like big crowds but when I am there I focus on the things I am interested in (the games) and…

Content:

> I don't like big crowds but when I am there I focus on the things I am interested in (the games) and that makes it easier to be around a lot of people.

1:107 I focus on the common interests that I have with people, or I focus on the game or my conversation p…

Content:

> I focus on the common interests that I have with people, or I focus on the game or my conversation partner so much that I don’t notice the crowd anymore. I also learned a breathing exercise which I do before I enter those situations and that really helps.

1:114 Individual therapy really helped me when I got bad mentally. My counsellor told me to do it and it h…

Content:

> Individual therapy really helped me when I got bad mentally. My counsellor told me to do it and it helped me calm down. I am in a more comfortable mind space now.

1:116 I don’t think treatment can be generalized, the treatment that I am doing can only be recommended to…

Content:

> I don’t think treatment can be generalized, the treatment that I am doing can only be recommended to people that have the same issues that I have.
> What advice I would give is difficult, too. It really depends on the previous history of the person and the age of diagnosis.

1:117 The only advice that I can give is that breathing techniques can help calming you down. And when you…

Content:

> The only advice that I can give is that breathing techniques can help calming you down. And when you feel uncomfortable in crowds, focus on something else that you like, that you are interested in, for me that would be board games. That works for me, but it might not work for others.

1:119 I advised her to go to ATN, told her that the waiting lists are long but that here she would get the…

Content:

> I advised her to go to ATN, told her that the waiting lists are long but that here she would get the help that she needs.

1:123 I think one of the biggest issues is that there is still such a big taboo around mental issues, no o…

Content:

> I think one of the biggest issues is that there is still such a big taboo around mental issues, no one talks about it. I think that needs to change, people need to talk about their mental struggle more.

3:37 One of the things I learned to do more is to look at people while I am talking. It feels really unna…

Content:

> One of the things I learned to do more is to look at people while I am talking. It feels really unnatural to do it but I learned it by talking a lot and being in school.

3:60 I have sound-blocking headphones

Content:
> I have sound-blocking headphones

3:64 But if I can focus on one thing and I am sheltered enough from outside noises I can focus really wel…

Content:
> But if I can focus on one thing and I am sheltered enough from outside noises I can focus really well and do a lot of work. I need to have the conditions to deal with it though.

3:83 I really like to just be home for a day for example. I work 4 days a week, I am free on Wednesdays.…

Content:
> I really like to just be home for a day for example. I work 4 days a week, I am free on Wednesdays. Which is good for me because it cuts the week in half. I have the day for myself, to sleep in, to recharge, to do things I want to do. It helps to take time, to take it easy.

3:85 And to make sure that things which require a lot of energy for me, like driving a car, are well plan…

Content:
> And to make sure that things which require a lot of energy for me, like driving a car, are well planned. I need to make sure to get enough rest. I need to know what I can do and can not do and plan it.

3:87 I wear headphones sometimes. And I am really mindful about what I am doing and avoid situations that…

Content:
> I wear headphones sometimes. And I am really mindful about what I am doing and avoid situations that are too much for me.

3:88 I think most of them I experienced myself. And I believe that is also the only way to do it. To just…

Content:
> I think most of them I experienced myself. And I believe that is also the only way to do it. To just experience on an energy level what is good for you and what is too much. And when you step over a boundary you notice it afterwards and then reflect on what was too much and learn from it.

3:92 Mindfulness meditation really helps to quieten down your thoughts and change your way of thinking. I…

Content:
> Mindfulness meditation really helps to quieten down your thoughts and change your way of thinking. I am using an app, I don’t remember how I found out about it, maybe I found it myself, maybe someone recommended it to me.

negative impact

10 Codes:

- **Bad mental state**

12 Quotations:

1:17 when I did my teacher study (“LVO”), I was 21/22, my mental state went bad and I had to quit because…

Content:

> when I did my teacher study (“LVO”), I was 21/22, my mental state went bad and I had to quit because it was too taxing. I actually stopped doing anything for a while. So I was at home for 2 years and my mental state dropped, I don’t want to go in detail, so let’s just say it got really bad

1:25 I ended up here (at “ATN”) because I wasn’t in a good mental space.

Content:

> I ended up here (at “ATN”) because I wasn’t in a good mental space.

1:47 Also for my classmates, people started crying and left the study often because it was too much.

Content:

> Also for my classmates, people started crying and left the study often because it was too much.

1:50 I literally lost faith! That is where the mental damage started. I was so stressed to find something…

Content:

> I literally lost faith!
> That is where the mental damage started. I was so stressed to find something, I contacted so many companies myself and no one helped me, the phone was never answered.

1:54 It was the worst.

Content:

> It was the worst.

1:83 they both made me feel like I could never become a teacher and made me quit my studies. All the time…

Content:

> they both made me feel like I could never become a teacher and made me quit my studies. All the time I was thinking “this can’t be happening, is this really happening?”, even on the train home it felt like an alternate reality.

1:87 they told me that what happened there is not formal policy, it was discrimination and I should’ve fo…

Content:

> they told me that what happened there is not formal policy, it was discrimination and I should've fought it. Maybe I should have but back then I was too low mentally to fight against it.

1:105 That was bad

Content:

> That was bad

1:122 I felt like they could have prevented her from feeling so bad and dropping out of her internship.

Content:

> I felt like they could have prevented her from feeling so bad and dropping out of her internship.

3:15 I got panic attacks and did not want to go to school anymore.

Content:

> I got panic attacks and did not want to go to school anymore.

3:26 I think I was never comfortable in school, I had stomach aches in the mornings, that I remember real…

Content:

> I think I was never comfortable in school, I had stomach aches in the mornings, that I remember really clearly. I didn't like "Sintaklaas" because of the surprises. I once got a "dirty" present and had such a bad panic attack that I went into my mothers class, who was watching a movie with their students and I sat there for the rest of the day because I had so much fear that was all I could do.

3:62 The feeling screams really loud in my mind and it makes it difficult to focus. That in combination w…

Content:

> The feeling screams really loud in my mind and it makes it difficult to focus. That in combination with hypochondria is really intense for me.

- ○ **Discrimination**

6 Quotations:

1:45 the teacher study I did was just less of a study and more like a bootcamp. We had exams and papers a…

Content:

> the teacher study I did was just less of a study and more like a bootcamp. We had exams and papers and classes and projects to do all at the same time. It was just too taxing. Also for my classmates, people started crying and left the study often because it was too much. Every two weeks we'd have to meet our "mentor" and present our grades and he would say: "Only above 7 points? That is not good enough, you can do better, that is a bad grade...!" So on one point it was too much and I was done with it. I don't understand the logic, he made me feel like I was not good enough, like I wasn't able to do the study.

1:59 I know someone, he would get psychotic when under stress, and when he disclosed himself he was not h…

Content:

> I know someone, he would get psychotic when under stress, and when he disclosed himself he was not helped at all, he was discriminated against and it ended really bad for him, he had to do an extra year of studying just because they thought he wasn't able to do it even though he was. In the end I was a witness for him when he filed a complaint against his school.

1:82 But in my first study I disclosed the DCD diagnosis to my mentor because I wasn't doing well, I had…

Content:

> But in my first study I disclosed the DCD diagnosis to my mentor because I wasn't doing well, I had too little ECTS and wouldn't make eye contact with people. So I told him that DCD is the reason. He said that people who have this cannot become teachers and really talked me down. Then he took me to the dean and they both made me feel like I could never become a teacher and made me quit my studies. All the time I was thinking "this can't be happening, is this really happening?", even on the train home it felt like an alternate reality.

1:95 They would think "Oh, no let's help that person." but then treat you like a child. I had a friend wh…

Content:

> They would think "Oh, no let's help that person." but then treat you like a child. I had a friend who disclosed her ASD in school and that is what happened to her; she was treated like a kid.

1:96 Because of the stereotypes in the public media I think it is better not to disclose ASD because it w…

Content:

> Because of the stereotypes in the public media I think it is better not to disclose ASD because it would change people's attitudes in a negative, stigmatizing way.

1:103 And when I wanted to do my drivers license, they gave me a form with a checklist of issues or sympto…

Content:

> And when I wanted to do my drivers license, they gave me a form with a checklist of issues or symptoms applying to me, one of them was 'brain damage'. And I thought that doesn't apply to me, so I didn't put a cross. But then they found out about my ASD diagnosis and said they consider ASD as brain damage so I couldn't do my drivers license. That was bad.

○ **Disruption**

6 Quotations:

1:19 My entire life I was told that I don't have ASD but DCD but then, here, they told me that DCD did no…

Content:

> My entire life I was told that I don't have ASD but DCD but then, here, they told me that DCD did not exist anymore. It was apparently now considered to be part of ASD, so they did a brief test, like 30 minutes, and then said "Yeah, you got it.". It still feels like I don't.

1:26 They literally told me because of budget cuts "DCD" doesn't exist anymore, so they put it "on one pi…

Content:

> They literally told me because of budget cuts "DCD" doesn't exist anymore, so they put it "on one pile".

1:40 But then the diagnosis they gave me, that fit me, doesn't exist anymore because of money?

Content:

> But then the diagnosis they gave me, that fit me, doesn't exist anymore because of money?

1:76 After the ASD diagnosis I stopped telling people about DCD too.

Content:

> After the ASD diagnosis I stopped telling people about DCD too.

3:12 And when I was in the 5th grade, we moved to another building in the same village because the school…

Content:

> And when I was in the 5th grade, we moved to another building in the same village because the school was under construction. And apparently that caused some issues for me.

3:15 I got panic attacks and did not want to go to school anymore.

Content:

> I got panic attacks and did not want to go to school anymore.

○ Internalized stigma

0 Quotations

○ Lack of psychoeducation

14 Quotations:

1:21 so they did a brief test, like 30 minutes, and then said "Yeah, you got it.".

Content:

> so they did a brief test, like 30 minutes, and then said "Yeah, you got it.".

1:26 They literally told me because of budget cuts "DCD" doesn't exist anymore, so they put it "on one pi…

Content:

> They literally told me because of budget cuts “DCD” doesn’t exist anymore, so they put it “on one pile”.

1:27 I: Didn’t they explain the concept of ASD to you? P: No, they just said: “now we can give you a coun…

Content:

> I:
> Didn’t they explain the concept of ASD to you?
> P:
> No, they just said: “now we can give you a counsellor”.

1:57 And also from the psychoeducation course I mentioned earlier. The media and the course portraits Aut…

Content:

> And also from the psychoeducation course I mentioned earlier. The media and the course portraits Autism so generalized, in such a stereotypical way. It says: “This is what autism is like, this is what you suffer from.”

1:61 I get frustrated and annoyed with the media because they take the typical picture of a little boy st…

Content:

> I get frustrated and annoyed with the media because they take the typical picture of a little boy staring into a snow globe and say that is what autism is like. The truth is that there are so many people falling into the category of autism and they can’t be generalized to the picture the media portrays. Autism is a spectrum and I for myself only recognize not liking touch, eye contact and big crowds, the rest doesn’t apply. So I stopped watching the media, they want it (ASD) to look like a spectacle so I just don’t watch it anymore.

1:74 I had a teacher once who was talking about traits of ASD and then said: “I should know what that mea…

Content:

> I had a teacher once who was talking about traits of ASD and then said: “I should know what that means, since I have a diagnosis myself.”. I didn’t expect that so it just shows that the diagnosis is also applied to people that don’t have all the symptoms and that don’t appear like they have ASD at all.

1:94 People only listen to the media and the stereotype of Autism shown there.

Content:

> People only listen to the media and the stereotype of Autism shown there.

1:98 It is difficult to change the mainstream image of ASD so it is better if people don’t know otherwise…

Content:

> It is difficult to change the mainstream image of ASD so it is better if people don’t know otherwise they will apply those stereotypes to you.

1:103 And when I wanted to do my drivers license, they gave me a form with a checklist of issues or sympto…

Content:

> And when I wanted to do my drivers license, they gave me a form with a checklist of issues or symptoms applying to me, one of them was ‘brain damage’. And I thought that doesn’t apply to me, so I didn’t put a cross. But then they found out about my ASD diagnosis and said they consider ASD as brain damage so I couldn’t do my drivers license. That was bad.

3:20 K: What about the word autism, did they explain to you what it meant? P: No, I don’t really think th…

Content:

> K:
> What about the word autism, did they explain to you what it meant?
> P:
> No, I don’t really think they did.

3:46 That is really difficult because you can explain to them what it is but sometimes they just don’t kn…

Content:

> That is really difficult because you can explain to them what it is but sometimes they just don’t know that it is different for everyone.

3:48 Yes I think so because of movies and tv shows that show it in a certain, very extreme way. I assume…

Content:

> Yes I think so because of movies and tv shows that show it in a certain, very extreme way. I assume that the image people have of autism is influenced by that. So I think they judge more if they only know that image

3:51 So yes, I think the less they know the more judgemental they are.

Content:

> So yes, I think the less they know the more judgemental they are.

3:70 On the news usually autism is not talked about, unless there is an extraordinary success story of so…

Content:

> On the news usually autism is not talked about, unless there is an extraordinary success story of someone with autism.

○ Lack of self-efficacy

7 Quotations:

1:18 it was too taxing. I actually stopped doing anything for a while.

Content:

> it was too taxing. I actually stopped doing anything for a while.

1:46 It was just too taxing.

Content:

> It was just too taxing.

1:48 So on one point it was too much and I was done with it. I don't understand the logic, he made me fee…

Content:

> So on one point it was too much and I was done with it. I don't understand the logic, he made me feel like I was not good enough, like I wasn't able to do the study.

1:84 they both made me feel like I could never become a teacher and made me quit my studies.

Content:

> they both made me feel like I could never become a teacher and made me quit my studies.

1:87 they told me that what happened there is not formal policy, it was discrimination and I should've fo…

Content:

> they told me that what happened there is not formal policy, it was discrimination and I should've fought it. Maybe I should have but back then I was too low mentally to fight against it.

1:102 Challenges are that I don't really enjoy going out, I am not able to be in big crowds. That really h…

Content:

> Challenges are that I don't really enjoy going out, I am not able to be in big crowds. That really hampers me.

1:122 I felt like they could have prevented her from feeling so bad and dropping out of her internship.

Content:

> I felt like they could have prevented her from feeling so bad and dropping out of her internship.

○ Lack of self-esteem

4 Quotations:

1:48 So on one point it was too much and I was done with it. I don't understand the logic, he made me fee…

Content:

> So on one point it was too much and I was done with it. I don't understand the logic, he made me feel like I was not good enough, like I wasn't able to do the study.

1:84 they both made me feel like I could never become a teacher and made me quit my studies.

Content:

> they both made me feel like I could never become a teacher and made me quit my studies.

1:87 they told me that what happened there is not formal policy, it was discrimination and I should’ve fo…

Content:

> they told me that what happened there is not formal policy, it was discrimination and I should’ve fought it. Maybe I should have but back then I was too low mentally to fight against it.

1:102 Challenges are that I don’t really enjoy going out, I am not able to be in big crowds. That really h…

Content:

> Challenges are that I don’t really enjoy going out, I am not able to be in big crowds. That really hampers me.

○ Lack of social support

4 Quotations:

1:49 In my next study, I was only the second generation of people doing it. So no one knew how things wor…

Content:

> In my next study, I was only the second generation of people doing it. So no one knew how things worked, the communication was really bad and there were internal fights that I can not say too much about. There was just a lot of struggle and a lot of classes that didn’t make sense. And then we had to do an internship. For 7 months before there was no communication and information about it, except that they said they would help us with it. And then 1 week before it started they said they wouldn’t help us anymore and I literally lost faith!

1:51 I was so stressed to find something, I contacted so many companies myself and no one helped me, the…

Content:

> I was so stressed to find something, I contacted so many companies myself and no one helped me, the phone was never answered.

1:53 The internship was bad then too, the company went bankrupt and piled work on me, they went down and…

Content:

> The internship was bad then too, the company went bankrupt and piled work on me, they went down and they wanted someone to fix it, that someone was me. It was the worst.

1:121 “STUMAS” dropped her from what I felt like, they were supposed to help her but I was the only one wh…

Content:

> “STUMAS” dropped her from what I felt like, they were supposed to help her but I was the only one who noticed she was struggling. I think they fell short on helping her but I can’t tell for sure either. I felt like they could have prevented her from feeling so bad and dropping out of her internship.

○ No Acceptance

6 Quotations:

1:20 It still feels like I don’t.

Content:

> It still feels like I don’t.

1:37 I do “fight” with the ASD diagnosis in the sense of I don’t accept it.

Content:

> I do “fight” with the ASD diagnosis in the sense of I don’t accept it.

1:39 But then the diagnosis they gave me, that fit me, doesn’t exist anymore because of money? I don’t re…

Content:

> But then the diagnosis they gave me, that fit me, doesn’t exist anymore because of money? I don’t recognize myself in the ASD diagnosis, I had psychoeducation about it and they showed us slides with symptoms, about what ASD is. And I don’t recognize any of it. I don’t have trouble reading people's emotions, I have no trouble understanding people or making jokes, or understanding sarcasm. I was
>
> Interview Participant 1 17.05.2020
> told that people with ASD, so including me, have major issues with social situations, but they made it seem a lot harder than it is for me. So I don’t recognize myself in it. I’ve also never experienced sensory overstimulation. I still don’t feel like I have it (ASD).

1:44 But I do mentally struggle with the diagnosis. I go into defense mode when I hear about it, because…

Content:

> But I do mentally struggle with the diagnosis. I go into defense mode when I hear about it, because I don’t see myself that way.

1:68 I never tell anyone about my ASD diagnosis, I don’t feel like I have it so why would I say it?

Content:

> I never tell anyone about my ASD diagnosis, I don’t feel like I have it so why would I say it?

1:99 There are only 3 things you need to know about me, and those are not the diagnosis ASD

Content:

> There are only 3 things you need to know about me, and those are not the diagnosis ASD

- **Social stigma**

10 Quotations:

1:56 I don’t think I ever felt judged personally, but from the media, yes. And also from the psychoeducat…

Content:

> I don’t think I ever felt judged personally, but from the media, yes. And also from the psychoeducation course I mentioned earlier. The media and the course portraits Autism so generalized, in such a stereotypical way. It says: “This is what autism is like, this is what you suffer from.” And I am like: “No, I don’t. I don’t relate to it!”.

1:59 I know someone, he would get psychotic when under stress, and when he disclosed himself he was not h…

Content:

> I know someone, he would get psychotic when under stress, and when he disclosed himself he was not helped at all, he was discriminated against and it ended really bad for him, he had to do an extra year of studying just because they thought he wasn’t able to do it even though he was. In the end I was a witness for him when he filed a complaint against his school.

1:61 I get frustrated and annoyed with the media because they take the typical picture of a little boy st…

Content:

> I get frustrated and annoyed with the media because they take the typical picture of a little boy staring into a snow globe and say that is what autism is like. The truth is that there are so many people falling into the category of autism and they can’t be generalized to the picture the media portrays. Autism is a spectrum and I for myself only recognize not liking touch, eye contact and big crowds, the rest doesn’t apply. So I stopped watching the media, they want it (ASD) to look like a spectacle so I just don’t watch it anymore.

1:82 But in my first study I disclosed the DCD diagnosis to my mentor because I wasn’t doing well, I had…

Content:

> But in my first study I disclosed the DCD diagnosis to my mentor because I wasn’t doing well, I had too little ECTS and wouldn’t make eye contact with people. So I told him that DCD is the reason. He said that people who have this cannot become teachers and really talked me down. Then he took me to the dean and they both made me feel like I could never become a teacher and made me quit my studies. All the time I was thinking “this can’t be happening, is this really happening?”, even on the train home it felt like an alternate reality.

1:92 But with Autism, I don’t think it helps. People only listen to the media and the stereotype of Autis…

Content:

> But with Autism, I don’t think it helps. People only listen to the media and the stereotype of Autism shown there. They would think “Oh, no let’s help that person.” but then treat you like a child. I had a friend who disclosed her ASD in school and that is what happened to her; she was treated like a kid. She was okay with it but I am not. Because of the

> stereotypes in the public media I think it is better not to disclose ASD because it would change people's attitudes in a negative, stigmatizing way. It is difficult to change the mainstream image of ASD so it is better if people don’t know otherwise they will apply those stereotypes to you.

1:103 And when I wanted to do my drivers license, they gave me a form with a checklist of issues or sympto…

Content:
> And when I wanted to do my drivers license, they gave me a form with a checklist of issues or symptoms applying to me, one of them was ‘brain damage’. And I thought that doesn’t apply to me, so I didn’t put a cross. But then they found out about my ASD diagnosis and said they consider ASD as brain damage so I couldn’t do my drivers license. That was bad.

3:41 It is something I still struggle with because people don’t understand what it really means, they don…

Content:
> It is something I still struggle with because people don’t understand what it really means, they don’t understand that autism is so different for everyone. They have a stereotypical perception of it. Some time ago there was a video on youtube of a kid and you saw what he sees, strong lights and intense colours. It is something I also experience, maybe not on that level though.

3:47 But if you drop the word autism, how are people going to react, what is their image of it? That is r…

Content:
> But if you drop the word autism, how are people going to react, what is their image of it? That is really difficult because you can explain to them what it is but sometimes they just don’t know that it is different for everyone.

3:48 Yes I think so because of movies and tv shows that show it in a certain, very extreme way. I assume…

Content:
> Yes I think so because of movies and tv shows that show it in a certain, very extreme way. I assume that the image people have of autism is influenced by that. So I think they judge more if they only know that image

3:51 So yes, I think the less they know the more judgemental they are.

Content:
> So yes, I think the less they know the more judgemental they are.

---

neutral

5 Codes:

- **ASD diagnosis**

35 Quotations:

1:22 ASD

Content:
> ASD

1:36 ASD diagnosis

Content:
> ASD diagnosis

1:65 Autism

Content:
> Autism

1:66 (ASD)

Content:
> (ASD)

1:67 autism

Content:
> autism

1:69 ASD diagnosis

Content:
> ASD diagnosis

1:75 ASD diagnosis

Content:
> ASD diagnosis

1:78 ASD

Content:
> ASD

1:79 ASD

Content:
> ASD

1:85 ASD diagnosis

Content:
> ASD diagnosis

1:90 I don’t disclose my Autism,

Content:
> I don’t disclose my Autism,

1:93 Autism,

Content:
> Autism,

1:97 ASD

Content:
> ASD

1:100 diagnosis ASD

Content:
> diagnosis ASD

1:104 ASD diagnosis

Content:
> ASD diagnosis

3:13 I was 10/12 when I got the diagnosis.

Content:
> I was 10/12 when I got the diagnosis.

3:17 we went to another autism center (for children). And there I got a proper diagnosis

Content:
> we went to another autism center (for children). And there I got a proper diagnosis

3:24 autism diagnosis

Content:
> autism diagnosis

3:30 Autism

Content:
> Autism

3:31 autism

Content:
> autism

3:45 autism,

Content:

> autism,

3:54 autism

Content:
> autism

3:55 autism.

Content:
> autism.

3:68 Sometimes I think it is a reason to be denied a job

Content:
> Sometimes I think it is a reason to be denied a job

3:76 autism

Content:
> autism

3:77 autism

Content:
> autism

3:100 Autism

Content:
> Autism

3:101 autism

Content:
> autism

3:103 autism.

Content:
> autism.

3:104 autism.

Content:
> autism.

3:105 Autism

Content:
> Autism

3:106 autism

Content:
> autism

3:107 autism

Content:
> autism

3:108 autism

Content:
> autism

3:109 autism.

Content:
> autism.

- **DCD diagnosis**

8 Quotations:

1:15 “DCD” diagnosis...

Content:
> “DCD” diagnosis...

1:23 DCD

Content:
> DCD

1:28 “DCD”

Content:
> “DCD”

1:33 “DCD” diagnosis

Content:
> “DCD” diagnosis

1:70 DCD

Content:
> DCD

1:77 DCD

Content:

> DCD

1:81 DCD i

Content:

> DCD i

1:91 with DCD people were supportive when I told them.

Content:

> with DCD people were supportive when I told them.

○ Disclosure

13 Quotations:

1:71 With DCD I did tell people around me, but usually I just told them that I have issues with eye conta…

Content:

> With DCD I did tell people around me, but usually I just told them that I have issues with eye contact, touch and big crowds. That was never an issue for anyone.

1:73 Sometimes people would guess that I have a diagnosis and then I admit it

Content:

> Sometimes people would guess that I have a diagnosis and then I admit it

1:80 But in my first study I disclosed the DCD diagnosis to my mentor because I wasn't doing well, I had…

Content:

> But in my first study I disclosed the DCD diagnosis to my mentor because I wasn't doing well, I had too little ECTS and wouldn't make eye contact with people. So I told him that DCD is the reason.

1:88 up until that point people I disclosed myself to were really supportive, also the teachers. And I de…

Content:

> up until that point people I disclosed myself to were really supportive, also the teachers. And I definitely need the support.

1:91 with DCD people were supportive when I told them.

Content:

> with DCD people were supportive when I told them.

3:5 they also know my brothers and my diagnoses

Content:

> they also know my brothers and my diagnoses

3:44 Usually I wait until the end to tell them that there are some things that I would need in order to w…

Content:
> Usually I wait until the end to tell them that there are some things that I would need in order to work better.

3:53 if I react a certain way and it can be explained with my autism, I explain it.

Content:
> if I react a certain way and it can be explained with my autism, I explain it.

3:66 So if I already feel that the other person is inclined to understand it, then I am comfortable to te…

Content:
> So if I already feel that the other person is inclined to understand it, then I am comfortable to tell them. So sometimes I tell them up front, sometimes I wait until the end.
>
> Interview Participant 2 27.05.2020
> For my coming job interview, I already told the recruiter, but not the manager that I will have the actual interview with. So they know at a certain level. I also did a personality test, which they could conclude it from.

3:74 I usually stick to the most general things that people know about autism. For the work environment,…

Content:
> I usually stick to the most general things that people know about autism. For the work environment, I talk about the intensity of stimuli.

3:75 I try to explain it accordingly, so people get a sense for how I work. I tell them what applies to m…

Content:
> I try to explain it accordingly, so people get a sense for how I work. I tell them what applies to me and what I need in my environment. I don't drop my autism out of thin air but in the context of what I need. But then I do tell them, in a practical context.

3:79 I think some of them know. I have a friend from Serbia. I suspect that he might also have some kind…

Content:
> I think some of them know. I have a friend from Serbia. I suspect that he might also have some kind of autism.

3:82 When those issues are related to autism I can explain it to them in that way, that there are certain…

Content:
> When those issues are related to autism I can explain it to them in that way, that there are certain things about me that should be taken into account.

○ No disclosure

5 Quotations:

1:58 They told me in the course to go to school and tell them that I have autism but I don’t want to! I d…

Content:

> They told me in the course to go to school and tell them that I have autism but I don’t want to! I did not trust anyone. I know someone, he would get psychotic when under stress, and when he disclosed himself he was not helped at all, he was discriminated against and it ended really bad for him, he had to do an extra year of studying just because they thought he wasn’t able to do it even though he was. In the end I was a witness for him when he filed a complaint against his school. So I don’t believe that disclosure helps, I think it makes things worse.

1:68 I never tell anyone about my ASD diagnosis, I don’t feel like I have it so why would I say it?

Content:

> I never tell anyone about my ASD diagnosis, I don’t feel like I have it so why would I say it?

1:90 I don’t disclose my Autism,

Content:

> I don’t disclose my Autism,

1:98 It is difficult to change the mainstream image of ASD so it is better if people don’t know otherwise…

Content:

> It is difficult to change the mainstream image of ASD so it is better if people don’t know otherwise they will apply those stereotypes to you.

1:109 I don’t say anything but I deal with it in my head for the next half an hour.

Content:

> I don’t say anything but I deal with it in my head for the next half an hour.

○ receiving diagnosis

10 Quotations:

1:14 I received a “DCD” diagnosis...

Content:

> I received a “DCD” diagnosis...

1:21 so they did a brief test, like 30 minutes, and then said “Yeah, you got it.”.

Content:

> so they did a brief test, like 30 minutes, and then said “Yeah, you got it.”.

1:26 They literally told me because of budget cuts “DCD” doesn’t exist anymore, so they put it “on one pi…

Content:
> They literally told me because of budget cuts “DCD” doesn’t exist anymore, so they put it “on one pile”.

1:34 that’s why I got the diagnosis (DCD).

Content:
> that’s why I got the diagnosis (DCD).

1:42 I never really fought against the diagnosis though because it gives me so many benefits,

Content:
> I never really fought against the diagnosis though because it gives me so many benefits,

1:85 ASD diagnosis

Content:
> ASD diagnosis

1:89 So considering the pro’s and con’s, there are more benefits to me having a diagnosis because it allo…

Content:
> So considering the pro’s and con’s, there are more benefits to me having a diagnosis because it allows me to get the support I need.

3:13 I was 10/12 when I got the diagnosis.

Content:
> I was 10/12 when I got the diagnosis.

3:17 we went to another autism center (for children). And there I got a proper diagnosis

Content:
> we went to another autism center (for children). And there I got a proper diagnosis

3:23 So I have an autism diagnosis but also a generalized anxiety disorder diagnosis.

Content:
> So I have an autism diagnosis but also a generalized anxiety disorder diagnosis.

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positive impact

6 Codes:
- **Acceptance**

10 Quotations:

1:31 See, I was satisfied with my “DCD” diagnosis. I did feel different from others, that’s why I got the…

Content:

> See, I was satisfied with my “DCD” diagnosis. I did feel different from others, that’s why I got the diagnosis (DCD). One of the symptoms is feeling out of breath, like you’re choking when you are in big groups. I definitely have that. I also have issues with being touched, I only like it in very specific situations, that I don’t want to go in detail about now. I don’t like eye contact either, but that’s it. I was fine with it, that is who I am.

1:101 the symptoms I told you about. They are part of me,

Content:

> the symptoms I told you about. They are part of me,

3:21 I think I kind of grew into it. It was not a clear line for me. I imagine someone getting a cancer d…

Content:

> I think I kind of grew into it. It was not a clear line for me. I imagine someone getting a cancer diagnosis and being shocked. It was not like that for me. The more I understood about it, the more I felt like it was just something I had.

3:27 I don’t think there was a difference between before and after the diagnosis though. The diagnosis wa…

Content:

> I don’t think there was a difference between before and after the diagnosis though. The diagnosis was not a clear line because no one said to me ‘you have autism’. Maybe that would’ve been nice early on. But over time I started to understand what it means.

3:28 I think it is a part of me and I know how to live with certain things coming with it. And I know it…

Content:

> I think it is a part of me and I know how to live with certain things coming with it. And I know it prohibits me to do certain things. At a certain point you learn that some things are better for you than other things. I don’t know, it’s just my life. And it is a big part of my life but I don’t say: “I am Joris, I have Autism.” It’s not something I write down on my ID card.

3:34 I: So you say autism is a spectrum and some parts you relate to and those you also see as part of yo…

Content:

> I:
> So you say autism is a spectrum and some parts you relate to and those you also see as part of yourself?
> P: Yes.

3:36 there are some parts of the show that I can relate to really well

Content:

> there are some parts of the show that I can relate to really well

3:81 Autism matters more when people expect things from you, if they want something from me and it does n…

Content:

> Autism matters more when people expect things from you, if they want something from me and it does not go the way they want it to. When those issues are related to autism I can explain it to them in that way, that there are certain things about me that should be taken into account.

3:97 I would say it is a big part of my life. Yes, I think it is a part of my identity. The parts of auti…

Content:

> I would say it is a big part of my life. Yes, I think it is a part of my identity. The parts of autism that I recognize in myself are definitely part of who I am.

3:99 I think I mean more; is it explainable through it. That is a better way to put it. Autism is a part…

Content:

> I think I mean more; is it explainable through it. That is a better way to put it. Autism is a part of me, but is the behaviour from the part that is 'autistic'. Parts of myself I can recognize in the category of what autism is, so the way I think about it is that it explains parts of myself.

○ Continuity

6 Quotations:

1:16 I showed some signs at a very young age,

Content:

> I showed some signs at a very young age,

1:32 I did feel different from others, that's why I got the diagnosis (DCD). One of the symptoms is feeli…

Content:

> I did feel different from others, that's why I got the diagnosis (DCD). One of the symptoms is feeling out of breath, like you're choking when you are in big groups. I definitely have that. I also have issues with being touched, I only like it in very specific situations, that I don't want to go in detail about now. I don't like eye contact either, but that's it. I was fine with it, that is who I am.

3:18 I: Do you remember how and when you really understood that you were given an autism diagnosis? P: I…

Content:

> I:
> Do you remember how and when you really understood that you were given an autism diagnosis?
> P:

> I realized I was having troubles, so the older I got the more I became more conscious of why that was happening. That was probably somewhere around high school, when I mostly connected the dots.

3:21 I think I kind of grew into it. It was not a clear line for me. I imagine someone getting a cancer d…

Content:

> I think I kind of grew into it. It was not a clear line for me. I imagine someone getting a cancer diagnosis and being shocked. It was not like that for me. The more I understood about it, the more I felt like it was just something I had.

3:22 I: Do you remember how you perceived yourself before the diagnosis? Do you remeber if you ever felt…

Content:

> I:
> Do you remember how you perceived yourself before the diagnosis? Do you remeber if you ever felt different from other kids?
> P:
> Yes I think so. Especially looking back, when I was young I think I didn't have many friends and I didn't like to go to sleep overs, or playdates or parties later in high school. So I think that was a clear indication that there was something going on, and then I also had panic attacks and intense anxiety. (...)
> It was a mixture of things, the autism, the anxiety. So I have an autism diagnosis but also a generalized anxiety disorder diagnosis. I think I was never comfortable in school,

3:27 I don't think there was a difference between before and after the diagnosis though. The diagnosis wa…

Content:

> I don't think there was a difference between before and after the diagnosis though. The diagnosis was not a clear line because no one said to me 'you have autism'. Maybe that would've been nice early on. But over time I started to understand what it means.

○ Psychoeducation

11 Quotations:

1:41 I don't recognize myself in the ASD diagnosis, I had psychoeducation about it and they showed us sli…

Content:

> I don't recognize myself in the ASD diagnosis, I had psychoeducation about it and they showed us slides with symptoms, about what ASD is. And I don't recognize any of it. I don't have trouble reading people's emotions, I have no trouble understanding people or making jokes, or understanding sarcasm. I was
>
> Interview Participant 1 17.05.2020
> told that people with ASD, so including me, have major issues with social situations, but they made it seem a lot harder than it is for me. So I don't recognize myself in it. I've also never experienced sensory overstimulation. I still don't feel like I have it (ASD).

1:63 I know that they are not true and that the way they make it look is not who I am.

Content:

> I know that they are not true and that the way they make it look is not who I am.

1:106 I don’t think my brain is damaged, maybe some connections are different, but it is not damaged!

Content:

> I don’t think my brain is damaged, maybe some connections are different, but it is not damaged!

1:123 I think one of the biggest issues is that there is still such a big taboo around mental issues, no o…

Content:

> I think one of the biggest issues is that there is still such a big taboo around mental issues, no one talks about it. I think that needs to change, people need to talk about their mental struggle more.

3:4 they also know my brothers and my diagnoses. It’s generally well understood in the family and it giv…

Content:

> they also know my brothers and my diagnoses. It’s generally well understood in the family and it gives a certain freedom

3:32 I know that autism is a spectrum and it is really wide, a lot of different problems have the same la…

Content:

> I know that autism is a spectrum and it is really wide, a lot of different problems have the same label. I am not really socially awkward for example but my brother is. He doesn't talk about his feelings, I probably do it too much. I know that people have different forms of it. I think I can pick it out more easily, when I see people having social problems, sitting weirdly or not knowing how to respond or behave, I know how to respond to people like that.

3:35 The american show “The Good Doctor” is a good example. The doctor is really smart and socially awkwa…

Content:

> The american show “The Good Doctor” is a good example. The doctor is really smart and socially awkward, he is also autistic. And there are some parts of the show that I can relate to really well and then there are others that are very extreme and I don’t relate to.

3:49 the more they know the more they can see that we are all the same - we are all people. And everyone…

Content:

> the more they know the more they can see that we are all the same - we are all people. And everyone has some loose wires.

3:50 I think media portraits have become more in the last couple of years, also there is more education i…

Content:

> I think media portraits have become more in the last couple of years, also there is more education in schools. I am kind of sad that that didn't exist when I was younger, it would have helped.

3:56 There are a lot of people with autism in computer science and those people sometimes even do better.…

Content:

> There are a lot of people with autism in computer science and those people sometimes even do better. So there is a lot of appreciation for autism I think because it is known what these people do for the field / the company. So I think for my computer science it is maybe even a plus to have autism.

3:78 I usually stick to the most general things that people know about autism.

Content:

> I usually stick to the most general things that people know about autism.

○ **Self-efficacy**

27 Quotations:

1:1 I just finished school.

Content:

> I just finished school.

1:2 when I started I moved to groningen.

Content:

> when I started I moved to groningen.

1:4 I want to see my pet chicken at my parents home so I go there often.

Content:

> I want to see my pet chicken at my parents home so I go there often.

1:6 I still visit my grandmother as well

Content:

> I still visit my grandmother as well

1:9 we often play board games together.

Content:

> we often play board games together.

1:11 So about clubs and activities, I don't feel very comfortable in big groups so I've never really been…

Content:

> So about clubs and activities, I don't feel very comfortable in big groups so I've never really been part of a club but recently I discovered a side with people that enjoy
>
> Interview Participant 1 17.05.2020
> the same interest (I don't want to disclose what that is). I do meet people to play games with, and I go to the "Spiel Essen" each year and to the medieval events "Ter Apel". I don't like big crowds but when I am there I focus on the things I am interested in (the games) and that makes it easier to be around a lot of people.

1:30 I finished my studies now.

Content:

> I finished my studies now.

1:55 We started with over 200 students and in the end 20 of them graduated. One of them was me though, I…

Content:

> We started with over 200 students and in the end 20 of them graduated. One of them was me though, I just wanted to be done with it so I succeeded.

1:107 I focus on the common interests that I have with people, or I focus on the game or my conversation p…

Content:

> I focus on the common interests that I have with people, or I focus on the game or my conversation partner so much that I don't notice the crowd anymore. I also learned a breathing exercise which I do before I enter those situations and that really helps.

1:110 I do want to go out there and live my life though, so I enter challenging situations and try to deal…

Content:

> I do want to go out there and live my life though, so I enter challenging situations and try to deal with them nonetheless.

1:111 seems to get better, as a child I never made eye contact with anyone. Now I subconsciously try to do…

Content:

> seems to get better, as a child I never made eye contact with anyone. Now I subconsciously try to do it more often and I think it works. I also barely get the feeling of choking in crowds anymore

1:113 I can take touch now, under some very particular circumstances that I don't want to talk about furth…

Content:

> I can take touch now, under some very particular circumstances that I don't want to talk about further.

1:118 focus on something else that you like, that you are interested in, for me that would be board games.

Content:

> focus on something else that you like, that you are interested in, for me that would be board games.

3:2 I do groceries for them once a week now in Corona times. I am also helping them with their computer,…

Content:

> I do groceries for them once a week now in Corona times. I am also helping them with their computer, which they just bought.

3:6 I just finished school, I have a bachelors degree now in computer science. And I am currently workin…

Content:

> I just finished school, I have a bachelors degree now in computer science. And I am currently working at the place at which I did my final internship in the last half year. I am still there but I am looking for something else because I am not really happy with how it is going there.

3:9 I used to do sports with people but I can't now. I used to be in a swim club until 5 years ago, with…

Content:

> I used to do sports with people but I can't now. I used to be in a swim club until 5 years ago, with my nieces, so it was a family thing as well.
> This is also the reason why I joined the social skills training (here at ATN) because I want to do more outside of my family.

3:19 And now that I am getting older I notice more about what I can and can not do, what is good and bad…

Content:

> And now that I am getting older I notice more about what I can and can not do, what is good and bad for me etc. Holidays have always been a drag for me so I am not going on holidays anymore because they cost more energy than they give.

3:29 At a certain point you learn that some things are better for you than other things.

Content:

> At a certain point you learn that some things are better for you than other things.

3:37 One of the things I learned to do more is to look at people while I am talking. It feels really unna…

Content:

> One of the things I learned to do more is to look at people while I am talking. It feels really unnatural to do it but I learned it by talking a lot and being in school.

3:38 So I learned it and practiced it and I became better at it.

Content:

> So I learned it and practiced it and I became better at it.

3:63 if I can focus on one thing and I am sheltered enough from outside noises I can focus really well an…

Content:

> if I can focus on one thing and I am sheltered enough from outside noises I can focus really well and do a lot of work.

3:71 I don’t feel stigmatized by the media because I am really self-aware, I know what works for me and w…

Content:

> I don’t feel stigmatized by the media because I am really self-aware, I know what works for me and what doesn’t and I learned to talk openly to people around me and ask for what I need. I learned that that is the best way to cope with it. So I don’t feel stigmatized.

3:73 For me it is good and I know how to help myself but for other people it is more difficult.

Content:

> For me it is good and I know how to help myself but for other people it is more difficult.

3:84 So I really enjoy having that day off in the week and it is something I will be asking for in my job…

Content:

> So I really enjoy having that day off in the week and it is something I will be asking for in my job interview (later in the afternoon) as well, because I really want to keep it this way. It works well for me. And also for them, when I feel better I do a better job.

3:85 And to make sure that things which require a lot of energy for me, like driving a car, are well plan…

Content:

> And to make sure that things which require a lot of energy for me, like driving a car, are well planned. I need to make sure to get enough rest. I need to know what I can do and can not do and plan it.

3:88 I think most of them I experienced myself. And I believe that is also the only way to do it. To just…

Content:

> I think most of them I experienced myself. And I believe that is also the only way to do it. To just experience on an energy level what is good for you and what is too much. And when you step over a boundary you notice it afterwards and then reflect on what was too much and learn from it.

3:90 I think if I do the work we discussed I should do and I make sure I keep myself happy, what does he…

Content:

> I think if I do the work we discussed I should do and I make sure I keep myself happy, what does he care? So that is one reason why I am thinking about switching my job.

○ Self-esteem

16 Quotations:

1:35 I was fine with it, that is who I am.

Content:

> I was fine with it, that is who I am.

1:38 From time to time I think 'why can't I be normal', but very rarely. Mostly I am okay with not liking…

Content:

> From time to time I think 'why can't I be normal', but very rarely. Mostly I am okay with not liking big groups, eye contact and touch.

1:55 We started with over 200 students and in the end 20 of them graduated. One of them was me though, I…

Content:

> We started with over 200 students and in the end 20 of them graduated. One of them was me though, I just wanted to be done with it so I succeeded.

1:60 I go into a defense mode, because I don't accept what the media (or the course) makes autism look li…

Content:

> I go into a defense mode, because I don't accept what the media (or the course) makes autism look like for myself.

1:62 They don't make me feel bad about myself because I know that they are not true and that the way they…

Content:

> They don't make me feel bad about myself because I know that they are not true and that the way they make it look is not who I am.

1:106 I don't think my brain is damaged, maybe some connections are different, but it is not damaged!

Content:

> I don't think my brain is damaged, maybe some connections are different, but it is not damaged!

1:111 seems to get better, as a child I never made eye contact with anyone. Now I subconsciously try to do…

Content:

> seems to get better, as a child I never made eye contact with anyone. Now I subconsciously try to do it more often and I think it works. I also barely get the feeling of choking in crowds anymore

1:113 I can take touch now, under some very particular circumstances that I don’t want to talk about furth…

Content:

> I can take touch now, under some very particular circumstances that I don’t want to talk about further.

1:115 I am in a more comfortable mind space now.

Content:

> I am in a more comfortable mind space now.

3:38 So I learned it and practiced it and I became better at it.

Content:

> So I learned it and practiced it and I became better at it.

3:58 That is a part of logic and it is something I can generally do really well so I do see it as a benef…

Content:

> That is a part of logic and it is something I can generally do really well so I do see it as a benefit.

3:63 if I can focus on one thing and I am sheltered enough from outside noises I can focus really well an…

Content:

> if I can focus on one thing and I am sheltered enough from outside noises I can focus really well and do a lot of work.

3:71 I don’t feel stigmatized by the media because I am really self-aware, I know what works for me and w…

Content:

> I don’t feel stigmatized by the media because I am really self-aware, I know what works for me and what doesn’t and I learned to talk openly to people around me and ask for what I need. I learned that that is the best way to cope with it. So I don’t feel stigmatized.

3:72 It makes me feel good about myself.

Content:

> It makes me feel good about myself.

3:73 For me it is good and I know how to help myself but for other people it is more difficult.

Content:

> For me it is good and I know how to help myself but for other people it is more difficult.

3:84 So I really enjoy having that day off in the week and it is something I will be asking for in my job…

Content:

> So I really enjoy having that day off in the week and it is something I will be asking for in my job interview (later in the afternoon) as well, because I really want to keep it this way. It works well for me. And also for them, when I feel better I do a better job.

○ Social support

36 Quotations:

1:3 I go to my parents every weekend, before I started studying I lived at home

Content:

> I go to my parents every weekend, before I started studying I lived at home

1:5 My social network is based around Groningen. I still visit my grandmother as well, we sometimes go o…

Content:

> My social network is based around Groningen. I still visit my grandmother as well, we sometimes go out together,

1:7 My social network is mainly based on the city of Groningen. I have one good friend in Groningen

Content:

> My social network is mainly based on the city of Groningen.
> I have one good friend in Groningen

1:8 I have one good friend where my parents live, we often play board games together.

Content:

> I have one good friend where my parents live, we often play board games together.

1:10 I have two classmates that I am still in touch with, one of them I have a professional relationship…

Content:

> I have two classmates that I am still in touch with, one of them I have a professional relationship with and one of them I have a social relationship with, I will see him this afternoon.
> I got along well with the people in school, we were often complaining about the study together, nothing better than sharing a common evil to make friends. We shared a lot of inside jokes.

1:11 So about clubs and activities, I don't feel very comfortable in big groups so I've never really been…

Content:

> So about clubs and activities, I don’t feel very comfortable in big groups so I’ve never really been part of a club but recently I discovered a side with people that enjoy
>
> Interview Participant 1 17.05.2020
> the same interest (I don’t want to disclose what that is). I do meet people to play games with, and I go to the “Spiel Essen” each year and to the medieval events “Ter Apel”. I don’t like big crowds but when I am there I focus on the things I am interested in (the games) and that makes it easier to be around a lot of people.

1:13 my mother took me to a psychologist, I guess she was worried because I wasn’t like the other kids.

Content:

> my mother took me to a psychologist, I guess she was worried because I wasn’t like the other kids.

1:24 I ended up here (at “ATN”) because I wasn’t in a good mental space. My mother is a social worker, an…

Content:

> I ended up here (at “ATN”) because I wasn’t in a good mental space. My mother is a social worker, and I think she noticed signs of a troubled teenager. Because she is my mother she couldn’t help me herself so she asked a colleague, but it was not her area of expertise. She then got referred to “talent-school” and they advised her to take me to ATN.

1:29 “now we can give you a counsellor”. She was really great though, she helped me a lot, also with stud…

Content:

> “now we can give you a counsellor”. She was really great though, she helped me a lot, also with studying, I actually miss her. She had to stop due to something, and I finished my studies now.

1:43 I never really fought against the diagnosis though because it gives me so many benefits, I am happy…

Content:

> I never really fought against the diagnosis though because it gives me so many benefits, I am happy with therapy, it ‘keeps me alive’ mentally

1:52 I live in an autism community so I decided to ask the “begeleiders” (translate = mentors) for help.…

Content:

> I live in an autism community so I decided to ask the “begeleiders” (translate = mentors) for help. When they called the company they did answer and I finally got an internship within a week.

1:72 That was never an issue for anyone.

Content:

> That was never an issue for anyone.

1:86 Years later, when I got help after the ASD diagnosis, they told me that what happened there is not f…

Content:

> Years later, when I got help after the ASD diagnosis, they told me that what happened there is not formal policy, it was discrimination and I should’ve fought it.

1:88 up until that point people I disclosed myself to were really supportive, also the teachers. And I de…

Content:

> up until that point people I disclosed myself to were really supportive, also the teachers. And I definitely need the support.

1:89 So considering the pro’s and con’s, there are more benefits to me having a diagnosis because it allo…

Content:

> So considering the pro’s and con’s, there are more benefits to me having a diagnosis because it allows me to get the support I need.

1:91 with DCD people were supportive when I told them.

Content:

> with DCD people were supportive when I told them.

1:114 Individual therapy really helped me when I got bad mentally. My counsellor told me to do it and it h…

Content:

> Individual therapy really helped me when I got bad mentally. My counsellor told me to do it and it helped me calm down. I am in a more comfortable mind space now.

1:120 I had a class-mate that I saw semi-regularly. When I saw her on one point I could really tell just b…

Content:

> I had a class-mate that I saw semi-regularly. When I saw her on one point I could really tell just by her eyes that she wasn’t doing well mentally. So I got to talk to her in a quiet moment when it was only her and me and I talked to her. After a while she told me herself that she wasn’t doing well and I advised her to go to ATN, told her that the waiting lists are long but that here she would get the help that she needs.

3:1 I currently still live at home. So I have my mother and my father, they are both teachers in middle…

Content:

> I currently still live at home. So I have my mother and my father, they are both teachers in middle education. My dad is an MBO teacher and my mom is a grade 3 teacher. And I live with my brother, he is 2 years younger than me, so he is 22 now. He also has autism. And I have my sister but she lives in her own room in the city. She is 20.

> So those are the people I am with mostly. I also have my grandparents who live a few streets away from my house and also the extended family, like aunts and uncles. I see them quite regularly. I do groceries for them once a week now in Corona times.

3:3 We're close and they are understanding, they also know my brothers and my diagnoses. It's generally…

Content:

> We're close and they are understanding, they also know my brothers and my diagnoses. It's generally well understood in the family and it gives a certain freedom for when we're away with the family in a large group for a weekend, that sometimes I am not joining activities because I need some time alone. So that's very nice.

3:7 But I have a really nice colleague who is the same age as me and my boss who is 30 / 35. I generally…

Content:

> But I have a really nice colleague who is the same age as me and my boss who is 30 / 35. I generally have good relationships with them but I don't see them outside work often. Sometimes I play a game with my colleagues but that's it. We're a really small team.

3:8 I used to do sports with people but I can't now. I used to be in a swim club until 5 years ago, with…

Content:

> I used to do sports with people but I can't now. I used to be in a swim club until 5 years ago, with my nieces, so it was a family thing as well.

3:10 I joined the social skills training (here at ATN)

Content:

> I joined the social skills training (here at ATN)

3:11 But I have friends with whom I'm gaming, from Norway, from Serbia, they are all over the world.

Content:

> But I have friends with whom I'm gaming, from Norway, from Serbia, they are all over the world.

3:14 I talked to my mom before about this, because my memory is not that great anymore.

Content:

> I talked to my mom before about this, because my memory is not that great anymore.

3:16 That is one of the reasons why we went to another autism center (for children). And there I got a pr…

Content:

> That is one of the reasons why we went to another autism center (for children). And there I got a proper diagnosis, I got some training and my parents got group therapy with other parents of children with autism.

> And since then I've been to mental health institutions every year for some kind of reason.

3:33 I know that people have different forms of it. I think I can pick it out more easily, when I see peo…

Content:

> I know that people have different forms of it.
> I think I can pick it out more easily, when I see people having social problems, sitting weirdly or not knowing how to respond or behave, I know how to respond to people like that.

3:40 So a lot of training was around the fear, Cognitive behavioural Therapy. I've done a lot of that.

Content:

> So a lot of training was around the fear, Cognitive behavioural Therapy. I've done a lot of that.

3:49 the more they know the more they can see that we are all the same - we are all people. And everyone…

Content:

> the more they know the more they can see that we are all the same - we are all people. And everyone has some loose wires.

3:50 I think media portraits have become more in the last couple of years, also there is more education i…

Content:

> I think media portraits have become more in the last couple of years, also there is more education in schools. I am kind of sad that that didn't exist when I was younger, it would have helped.

3:52 It is usually more the case that if I react a certain way and it can be explained with my autism, I…

Content:

> It is usually more the case that if I react a certain way and it can be explained with my autism, I explain it. So I haven't been discriminated against because of my autism.
> My field of study is also a very good environment for people with autism.
> There are a lot of people with autism in computer science and those people sometimes even do better. So there is a lot of appreciation for autism I think because it is known what these people do for the field / the company. So I think for my computer science it is maybe even a plus to have autism.

3:67 So if I already feel that the other person is inclined to understand it, then I am comfortable to te…

Content:

> So if I already feel that the other person is inclined to understand it, then I am comfortable to tell them.

3:80 I have a friend from Serbia. I suspect that he might also have some kind of autism. We talk about ce…

Content:

> I have a friend from Serbia. I suspect that he might also have some kind of autism. We talk about certain things in life, he is older than me and has about the same job as I do so I can also talk to him about my job. And he is really supportive in steps that I am taking which is really nice. And when I struggle he has some advice, so that is really cool.

3:93 I talk to my parents or my friends about issues, I like to talk to my therapist here as well because…

Content:

> I talk to my parents or my friends about issues, I like to talk to my therapist here as well because it adds another layer of reflection and insights.

3:94 I am doing PMT therapy now (Psychomotor therapy), it helps me to understand what I am feeling in my…

Content:

> I am doing PMT therapy now (Psychomotor therapy), it helps me to understand what I am feeling in my body because I am usually feeling a lot and I can overfocus on that. My mind then jumps to the conclusion that I am probably sick. So PMT helps to understand what I am feeling.

3:96 CBT helped me a lot for my anxiety and I am still keeping the mechanisms that I learned there. Socia…

Content:

> CBT helped me a lot for my anxiety and I am still keeping the mechanisms that I learned there. Social skills training helped me as well but I could not practice it a lot now because of Corona.

No code group

3 Codes:

○ GAD diagnosis

1 Quotations:

3:25 generalized anxiety disorder diagnosis

Content:

> generalized anxiety disorder diagnosis

○ Insight

11 Quotations:

1:125 I don’t feel very comfortable in big groups

Content:

> I don’t feel very comfortable in big groups

1:126 One of the symptoms is feeling out of breath, like you’re choking when you are in big groups. I defi…

Content:

> One of the symptoms is feeling out of breath, like you’re choking when you are in big groups. I definitely have that. I also have issues with being touched, I only like it in very specific situations, that I don’t want to go in detail about now. I don’t like eye contact either, but that’s it. I was fine with it, that is who I am.

1:127 I don’t have trouble reading people's emotions, I have no trouble understanding people or making jok…

Content:

> I don’t have trouble reading people's emotions, I have no trouble understanding people or making jokes, or understanding sarcasm.

3:71 I don’t feel stigmatized by the media because I am really self-aware, I know what works for me and w…

Content:

> I don’t feel stigmatized by the media because I am really self-aware, I know what works for me and what doesn’t and I learned to talk openly to people around me and ask for what I need. I learned that that is the best way to cope with it. So I don’t feel stigmatized.

3:73 For me it is good and I know how to help myself but for other people it is more difficult.

Content:

> For me it is good and I know how to help myself but for other people it is more difficult.

3:85 And to make sure that things which require a lot of energy for me, like driving a car, are well plan…

Content:

> And to make sure that things which require a lot of energy for me, like driving a car, are well planned. I need to make sure to get enough rest. I need to know what I can do and can not do and plan it.

3:88 I think most of them I experienced myself. And I believe that is also the only way to do it. To just…

Content:

> I think most of them I experienced myself. And I believe that is also the only way to do it. To just experience on an energy level what is good for you and what is too much. And when you step over a boundary you notice it afterwards and then reflect on what was too much and learn from it.

3:89 When those issues are related to autism I can explain it to them in that way, that there are certain…

Content:

> When those issues are related to autism I can explain it to them in that way, that there are certain things about me that should be taken into account.

> I learned that with experience.

3:93 I talk to my parents or my friends about issues, I like to talk to my therapist here as well because…

Content:

> I talk to my parents or my friends about issues, I like to talk to my therapist here as well because it adds another layer of reflection and insights.

3:95 it helps me to understand what I am feeling in my body because I am usually feeling a lot and I can…

Content:

> it helps me to understand what I am feeling in my body because I am usually feeling a lot and I can overfocus on that. My mind then jumps to the conclusion that I am probably sick.

3:99 I think I mean more; is it explainable through it. That is a better way to put it. Autism is a part…

Content:

> I think I mean more; is it explainable through it. That is a better way to put it. Autism is a part of me, but is the behaviour from the part that is 'autistic'. Parts of myself I can recognize in the category of what autism is, so the way I think about it is that it explains parts of myself.

○ positive aspects of autism

1 Quotations:

3:57 Detail orientation. A part of programming is that mistakes are preventable or to catch mistakes in y…

Content:

> Detail orientation. A part of programming is that mistakes are preventable or to catch mistakes in your code to run it. That is a part of logic and it is something I can generally do really well so I do see it as a benefit. Being focussed on doing your job and wanting to do it well, and thinking abstractly really helps as well when programming. And those are positive aspects of autism.