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Article · May 2017

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Configuring the autism epidemic

Why are so few girls diagnosed?

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Seeberg, Jens; Christensen, Fie Lund (2017). 'Configuring the autism epidemic: Why are so few girls diagnosed?' i *Tidsskrift for Forskning i Sygdom og Samfund*, nr. 26, 127-144

Autism has been described as an epidemic, but this claim is contested and may point to an awareness epidemic, i.e. changes in the definition of what autism is and more attention being invested in diagnosis leading to a rise in registered cases. The sex ratio of children diagnosed with autism is skewed in favour of boys, and girls with autism tend to be diagnosed much later than boys. Building and further developing the notion of 'configuration' of epidemics, this article explores the configuration of autism in Denmark, with a particular focus on the health system and social support to families with children diagnosed with autism, seen from a parental perspective.

The article points to diagnostic dynamics that contribute to explaining why girls with autism are not diagnosed as easily as boys. We unfold these dynamics through the analysis of a case of a Danish family with autism.

Is autism an epidemic?

Since Autism Spectrum Disorder (hereafter just 'autism') became an official diagnosis in Denmark in 1994, the number of people diagnosed with autism in Denmark has increased. Autism has gone from being a rare diagnosis to a diagnostic label that is assigned to one percent of the Danish population in 2014 (Videnrådet for Forbyggelse).

Autism is defined as a pervasive developmental disorder characterized by difficulties in social interaction, communication and stereotype/repetitive behaviour, interests and activities. Some people with autism also have intellectual difficulties (DSM5, ICD vol. 10). Signs of autism are sometimes seen from the child's infancy, but the diagnosis can be given at any age. The etiology of autism is unknown, but one or more genetic factors are assumed (Nicolson R. and Szatmari P. 2003). Since autism entered the American Diagnostic Statistical Manual of Mental Disorders (DSM) – the International Classification of Diseases (ICD) that is also used as the main diagnostic guideline in Danish psychiatry – there has been a significant increase in the number of people diagnosed with autism. However, historically, there are several earlier records of autism (Houston, 2000). Historical records of autism predate some of the contested potential etiological factors such as vaccines and certain environmental toxins. A case in point in the 18th century is that of Hugh Blair of Borgue (1708-1760), whose autism was identified by autism expert Uta Frith and Rab Houston (2000). Hugh Blair of Borgue's odd behaviour was recorded as part of a trial in 1737, where he was described as having weak communicative skills and a sociality that was awkward and inappropriate. For instance, he would socialize with servants and neighbours unaware that he was not welcome and was openly mocked by them. He displayed repetitive behaviours such as insisting on the same seat in church. Historical post-mortem diagnoses are based on contemporary behavioural descriptions and can obviously not be confirmed clinically.

While autism is not a new phenomenon, it is not clear why the number of people diagnosed has increased on global scale. Some explain this rise with factors such as local environmental toxins and vaccines, (Roberts, Eric M. 2007, Bernard, Sallie. 2004). Others have focused on cultural explanations for the epidemic. One such theory was formulated by the anthropologist Roy R. Grinker (2009), whose daughter is diagnosed with autism. He examined autism across the world and concluded in his book, *Isabel's World*, that the creation of the internet and the rise of child psychiatry, autism advocacy organisations and changes in public policies

altogether have created an awareness of autism and a focus on children's cognitive skills. This in turn has created an epidemic of discovery of autism among children. Therefore, he claims, the epidemic is not an epidemic understood as an actual increase of cases but an *awareness epidemic* caused by social dynamics. The sociologist Peter S. Bearman (2009) has tried to approach the epidemic from a related angle. Based on a study of statistical material on children's households in California he concluded that children who live close to another child with autism are significantly more likely to receive a diagnosis than children who live at a distance from people with autism. His main explanation of this is that awareness regarding how to navigate systems of diagnostics and social support is communicated among parents. Both Grinker and Bearman agree that it is not an epidemic of 'real autism', but an increase of diagnosed cases relative to a prior situation where they were overlooked. The historian Gil Eyal (2013) has argued that if we want to understand why autism is so prevalent now based on the assumption that autism has always been around, we need to ask why autism was so rare in the past. He suggests that autism was a rare disorder until mental retardation was deinstitutionalized and a new matrix with new actors appeared, where parents were considered experts on their children at par with psychologists and therapists.

If we accept these explanations, we may potentially understand the generalized increase in society. But whether or not we assume that we are looking at an increase of new cases or merely a decrease of diagnosed cases, we are not looking at something that has an even distribution in society. Cheryl Mattingly (forthcoming) suggests that class and ethnicity need to be taken into consideration as factors that influence the uneven spread of the diagnosis. A similar tendency may be found in Denmark according to the *Danish Knowledge-counseling for Prevention* (Vidensråd for forbyggelse), where people with low income have a higher occurrence of autism. Inequities regarding class and race are differentially articulated across societies, so these distinctions would presumably play out somewhat differently. However, here we wish to discuss a different dimension of the configuration of autism - that of gender. Boys with autism outnumber girls with autism anywhere in the world. Only one out of four children diagnosed with autism is a girl. No genetic factors have been identified that may explain this imbalance, and no cultural theory has yet taken up this issue in the debate of the autism epidemic, even if it seems to be of great importance to understand why some are less affected than others. In this article, we explore the social configuration of the autism epidemic in order to better understand the under-representation of girls with an autism diagnosis.

Configuring the autism epidemic

Rosenberg (1992) has analysed epidemics historically and has pointed to certain distinctive patterns though they are not mutually exclusive. He distinguishes two modes of explanation of epidemics through history: the contamination view and the configuration view (1992: 295ff.) Contamination implies a contagious agent, such as bacteria or a virus or poison. In the case of autism, contamination theories have been important for some activist organizations, including those who have claimed that vaccinations protecting against measles, mumps and rubella (MMR) could cause autism (Wakefield et al. 1998); however, despite a series of scientific investigations as well as a number of court cases in the US, this link has never been demonstrated (Fitzpatrick 2007). Currently, therefore, the contamination view has little to contribute to our understanding of the autism epidemic and its uneven distribution across class and gender.

Configuration, suggests Rosenberg, predates contamination theories because it does not require any understanding of an infectious agent. Configuration, in this understanding, explains epidemics as caused by a disturbance of the social order, implying a view of “health as a balanced, integrated, and value-imparting relationship between humankind and its environment” (Rosenberg, 1992: 295). Here, we would like to use the concept in a way that differs from Rosenberg’s, namely as an analytical concept as proposed by Seeberg and Meinert (2015). We would like to develop the concept further by contrasting it with the notion of context. As pointed out by Dilley (1999), contextualising is potentially boundless. Ultimately, the selection of what constitutes relevant context for a given analysis rests on the relationship of empirical material, theoretical framework and argument. Configuration may be considered as a form of context-making, but we propose to understand configuration as bounded by identifiable linkages of impact or influence, if not necessarily causality relative to the object of analysis, for example the dynamics of the autism epidemic. We do not suggest to replace context with configuration. A particular configuration of an epidemic is created by the co-existence of a range of conditions, events, processes, activities and interpretations that unfold in a given historical, socio-economic, environmental, local-global context. With the concept of configuration, we want to point to such co-existing conditions that drive a certain epidemic development. In this understanding, specific configurations of autism and its diagnostic practices becomes something to explore empirically: What does an understanding of the configuration of autism – even if partial – tell us about the uneven sex ratio of diagnosed children?

Girls with autism

The reasons for the lower rate of autism diagnoses amongst girls are unclear and contested. Some argue that a genetic component in the sex chromosomes makes boys more susceptible to autism (B. Robinson, Elise. et al. 2013). Such purely genetic explanations imply that the epidemic distribution is unaffected by cultural matters. Other researchers argue that there may be as many girls as boys with autism, claiming that girls are harder to diagnose (Kopp & Gillberg 1992, Wing, 1981, Andersen, 2011). Psychologists Lona Andersen and Svenny Kopp (2007) argue, that girls have better social skills and this makes them more difficult to diagnose since social skills are central in the diagnostic criteria, and thereby girls are consequently diagnosed in smaller numbers. A study by Dworzynski et al. among British children suggests a similar conclusion. They write that girls are less likely to be diagnosed with autism than boys are, unless they also have intellectual or behavioural problems (2012). The assumed better social skills of girls create other problems that might make it harder for significant others to identify problems before they appear as self-harm or eating disorders. Another important point is that girls are often wrongly diagnosed or diagnosed later in life than boys. According to a survey made by the Danish National Community for Autism, around 25% of the participating girls were wrongly diagnosed, before they got their autism diagnosis (Autismebladet 2014). Despite a growing attention on girls as a special diagnostic challenge, the lesser increase in girls has not been connected to the epidemic. If diagnosis of autism among girls is particularly challenging, it is important to understand the dynamics behind this and to ask what it can teach us about the autism epidemic. What seemingly makes girls less affected is equally interesting as what makes boys receive the diagnoses more frequently. Does susceptibility play a role, and if so, is it susceptibility to autism or to the diagnosis of autism? Rosenberg (1992) points to the historically important explanation of variation across individuals of disease during epidemics – how to explain that not everybody is affected? This has often been explained in terms of individual variation of predisposition, that is, it is not everybody who is equally able to attract or host a given disease at a given point in time: “Predisposition flexibly bridged the logical and emotional gap between individual and collective models of disease phenomena” (1992; 296). This notion is a precursor of the idea of immunity against epidemic disease and can explain what could otherwise seem arbitrary in terms of who is affected. Predisposition may be seen as an important mode of interpretation in the case of the Hansen family that we shall discuss below.

The Hansens

The material in this article is derived from a series of interviews conducted by the first author, Fie Lund Christensen, in 2014 consisting of approximately three hour-long semi-structured conversations with parents of children with autism. Here, we shall focus on one specific family, the Hansens, which consists of four people: Bente (mother), Tom (father), Mads (older son) and Anna (younger daughter)¹. Both Mads and Tom have been diagnosed with autism and the parents suspect that Anna may also have autism but she has not (yet) received a diagnosis.

The accounts of the members of the Hansen family describe how they have succeeded or failed in getting an autism diagnosis and provide insights into the configuration of diagnostic dimensions of the autism epidemic, for instance how different possibilities for identifying autism are created. The family's firstborn son, Mads, was the first to receive an autism diagnosis, but just like for the rest of his family, the road to an autism diagnosis contained varying interpretations of the problems surrounding him. An important part of the configuration of autism in the context of the Danish welfare state is the universal and free child health programme with its regular family visits to the family doctor to monitor the physical and mental development of the infant and young child in comparison to an expected 'normal' development.

Mads

When Mads turned three years old, he went for his annual medical check-up. Bente (the mother) asked the doctor if it was normal that "children watch movies inside their head". The doctor said that he did not know, but, according to Bente, he did not seem to be concerned by the question. As Bente puts it, she just wanted to make sure that it was not autism. Bente's point of reference was the American movie "Rainman" from 1988, which was released when she was a teenager. Bente told that Mads' problems increased when he started in kindergarten. He disappeared, when the children gathered in the wardrobe, hiding in the administration office. Mads wanted to play with the other children, but he did not understand the social rules and he often ended up in conflicts. During such confrontations it was hard for him to see his own share in the disputes and he was often frustrated. It had always been hard for Mads to change activity, but it became more and more difficult for him to manage changes. Routines were important for Mads. He beca-

me increasingly restless, and Bente explained how he “hung in the curtains and ran on the walls”. The kindergarten observed Mads’ behaviour and the problems it created when he was kicking, biting and hitting others. The kindergarten staff talked to the parents and they agreed to have Mads checked for ADHD since they believed this to be the most plausible explanation of his restlessness, the motoric problems as well as his extrovert behaviour. A special team got to observe Mads, consisting of a nurse and a pedagogue from the municipality. They concluded that there was nothing wrong with Mads.

Mads’ parents and the pedagogues in his kindergarten were surprised as they were certain that something was wrong with him. Tom and Bente tried to persuade their family doctor to help them take up the case, but this was not easy. In Denmark, childcare institutions may be ‘public’ or ‘private’, but in either case they are subsidized by the municipality and co-paid by the parents who use them. Hence, the municipal authorities are always involved in managing cases like that of Mads. But the authorities did not seem to take action and the kindergarten was overburdened and did not have the resources to take care of Mads’ special problems, so they applied for extra resources from the municipality to support Mads. Instead of this, the municipal authorities offered Mads to be placed in an established specialised kindergarten for children with ADHD - even though he did not have the diagnosis. The parents happily accepted the offer. At home, Mads’ life changed as he became a big brother. His new little sister, Anna, was born prematurely and a nurse was monitoring her closely. By coincidence, it happened to be the same nurse that had been part of Mads’ special observation team. Bente believed that Mads’ case had been closed, but one day the nurse brought a pedagogue to a meeting about Anna. They wanted to take an extra look at Mads, and this time they decided to test his cognitive skills. The test concluded that rather than ADHD Mads should be checked for autism. This came as a surprise to everybody who knew Mads and his challenges. He was referred to a psychiatric department for the purpose of testing for autism. During the diagnostic process, Tom and Bente were advised on new strategies to raise Mads, like reducing stress by making the day more predictable and structured by using visual schemas. This helped the family.

When Mads finally received his diagnosis, Bente had no doubt that it really was autism. During the diagnostic processes, she had learned what autism is and what strategies could help managing the child, and this made sense to her. She still had doubts about ADHD and to her surprise, the psychiatrist insisted that Mads only had autism and not ADHD. The new diagnosis justified that Mads

changed childcare institution to one specialised in autism, and within two weeks the symptoms of ADHD disappeared. At the time of the interview, his parents considered the ADHD symptoms to be signs of stress caused, for example, by irregular daily routines. The changes that Bente saw in Mads when they started to understand his autism and developed new strategies for their everyday lives have inspired her to help other parents navigate the system when suspecting their children may have autism.

Even if we understand autism as somehow localized in the individual, it often only becomes visible and recognised as a problem in the interplay with others. Like other mental diagnoses, autism is mirrored on a culturally embedded understanding of how to interact successfully at a certain age. But autism is also defined through institutionalized settings, special schools, public services and special upbringing models that all contribute to the creation of the configuration of the (awareness) epidemic. For the involved actors – psychiatrist, doctors, pedagogues and parents – it is an important task to identify potential diagnoses like autism to create access to the services needed. In the kindergarten staff, which are too overburdened to take care of a child with social problems, are motivated to help Mads' parents in their quest for a diagnosis. It is difficult for them to handle a child that cannot follow the everyday structure of for instance getting dressed in the wardrobe with other children and who constantly gets into fights with them. What starts as problems is transformed into symptoms in the process.

Symptoms are not limited to clinical settings, but have entered the everyday language as Brinkman (2010) notes. Symptoms have become a way of talking about and understanding problems. In everyday settings, problems like children running on the walls, hitting, and running away are increasingly interpreted as symptoms and a cause for professional concern. However, when cognitively tested, Mads' behaviour is interpreted in a different light, and a will to learn to interpret him as autistic replaces the interpretation related to the suspected ADHD diagnosis. Running on walls are now seen as symptoms of stress caused by autism rather than ADHD. The partially conflicting configurations of autism and ADHD that surround Mads and his parents contribute to his ADHD-like symptoms, not something that can be meaningfully located within him.

How can we understand the configuration that first results in his autism diagnosis and subsequently upholds it? We shall try to disaggregate, so to speak, some of the 'figures' that combine in the diagnostic configuration in Mads' case. One such figure is the insufficient resources allocated to childcare in Denmark, causing stress for both staff and children (Christoffersen et al. 2014). A child like

Mads is ill equipped to function well in such an environment, resulting in violent behaviour that further exacerbates his condition and motivates both staff and parents to search for a diagnosis that may result in allocation of additional resources in the kindergarten. However, the special team established to observe him does not suspect a medical condition and accordingly does not support this measure. Only because of a different figure, the special attention from the health system due to the premature birth of his little sister, further helped by the luck of having the same nurse for both children, Mads ends up with an autism diagnosis. Through special institutions, particular values regarding upbringing and knowledge passed on from the psychiatric department on Mads' behaviour, an interpretation of Mads as autistic is established. In that sense, autism is not just in the head of Mads but a reflection of the configuration of autism that surrounds him and that henceforth guide parents and other people in close contact with him regarding how to understand and interact with him. McDermott (1993) has noted that for learning disabilities contextual factors (what we might here call configuration) may exacerbate problems and negatively impact the learning disability, which Mads' case shows might be true for autism as well.

But in the Hansen family, Mads is not the only person for whom a diagnosis has been sought.

Tom

While Bente and Tom suspected that Mads had ADHD, Tom recognized some of the same problems in himself. He believed that he might also have ADHD, and so he went to his family doctor with his concern. He was then referred to a psychiatrist, who quickly diagnosed him with ADHD based on a diagnostic test and an interview about Tom's lifestory. This included one suicide attempt and a history of depression. After becoming a parent it had been hard for Tom to keep a job for a longer period, and he has had many jobs. The diagnostic process was fast, but certain things struck Tom as incoherent. For example, he never had any kind of motor restlessness. Nevertheless, he accepted the diagnosis, which he believed would allow him to work on reduced time and flexible hours. He felt he could not afford to question the ADHD diagnosis. When Mads received his autism diagnosis, Tom again went to his doctor to find out if he had autism. Twice, the doctor referred him to the local psychiatric department, but both times he was turned away because they did not have any services for adults. He then needed to con-

vince the local municipality to pay for a referral to another municipality. But according to Tom and Bente, the municipality did not acknowledge the need for another medical examination, since Tom already had one diagnosis. What could be won by a new one?

Five years later, Tom was still stuck with his ADHD diagnosis. Potentially, the family could pay for a private examination, but they did not have the money for it. Bente asked the municipality for a rejection in writing so that she could go to the press or demand a political response, but the municipality ignored her request. In 2015 when the interview was conducted, Bente and Tom said they were running out of energy fighting the system and would leave it for now. But within the family, they understood Tom as autistic. His way of seeing the world was used as a model for understanding Mads' behaviour. One year after the interview Tom succeeded in getting an Asperger diagnosis like Mads.

While there are clear differences in the way a three-year-old child and an adult are treated, there are also certain similarities at the level of the configurations of ADHD versus autism. Just like the case of Mads, an ADHD diagnosis was more readily available to Tom. Mads got into a specialised kindergarten for children with ADHD even before having received a diagnosis, while Tom accepted an ADHD diagnosis, not because he believed it to be correct, but because he thought he needed it. In contrast to Mads' case, it was Tom himself who identified his autism and not his surroundings – but he did so through the experience with Mads' condition and diagnosis. Tom himself subsequently defined his need for an autism diagnosis which created a conflict with the municipality since they could not see how an autism diagnosis could help him with his problems, since the perceived 'solution' – the flex job arrangement – had already been granted.

In the welfare state, a diagnosis is a precondition for certain social services. Parents of children who have special problems and need social services can find help from other parents in online fora. Here, parents like Bente share information of relevant services, rights and paragraphs to navigate the system. The Danish Council on Ethics points out in a recent report that this direct link between diagnoses and social services may be problematic (Etisk Råd, 2015). However, even if it was a need for a particular social service that made Tom accept his ADHD diagnosis, it was not the agenda for his pursuit of an autism diagnosis. At home, Tom's way of thinking was used as a model for understanding Mads, and this only makes sense if they shared the same diagnosis. What starts out as a diagnosis given to Mads by the system, ends up with the family being engaged in seeking diagnoses for other family members. Even though the family experienced resistance in the ef-

fort to get their autism diagnosis recognized in both Mads' and Tom's cases, they succeeded. In both cases, it was a decisive factor that somebody was sufficiently motivated by a perceived need for the diagnosis.

So far, we have discussed the configuration of the 'awareness epidemic' of autism, and above, we dismissed that relevance of the concept of contamination in attempts to explain the autism epidemic if seen as a dramatic increase of new cases. But what can we learn from the Hansen family about the role of contamination in the awareness epidemic of autism? It seems that there is some kind of contagion moving here in the opposite direction of genes, a kind of contamination from son to father. Combining Grinker's awareness with Bearman's communication, it makes sense to say that awareness is communicated. The father's close living with a person already diagnosed with autism makes him more likely to receive a similar diagnosis – it increases his susceptibility. It is common that once one person is diagnosed, several people within the same family receive the diagnosis or are treated as such by family members even if the diagnosis is not confirmed. This is sometimes explained with reference to the yet unknown genetic factors causing autism, where families find it plausible that more members would have the condition. If autism runs in the family, autism would be inherited from father to son in this case. But in the story of Tom and Mads this notion of causality may be questioned. Empirically, it seems that the father gets the diagnosis after his son has been diagnosed, both in the case of ADHD and autism. Obviously, the genetic explanation of disease transmission over generations and the cultural explanation of diagnosis transmission are not mutually exclusive. But if the autism epidemic is an awareness epidemic, we should be more concerned with the latter in terms of understanding it. Turning toward the family's daughter, Anna, who is undiagnosed but identified as autistic by her family. She is exposed to the same awareness and communication as her father and brother, but the family has not succeeded in achieving a diagnosis for her. What can this tell us about the gendering of the configuration of autism?

Anna

Like the two male members of the family, Anna had been in the spotlight for a long time, but she had no diagnosis and yet, Anna's parents had no doubt. They knew what autism looked like and they saw it clearly in her behaviour. Bente had 'acquitted' Anna for autism, as she put it, when she was a toddler because Anna

was much more socially competent than Mads. "But there is something that I just can't neglect", Bente explained. In kindergarten, Anna's cognitive skills were tested with the conclusion that she was premature and there was nothing wrong with her. Anna had problems with her gross motor functions, she had a hard time getting dressed and started walking late at an age of 22 months. Three physical therapists concluded that she had hypermobile joints, after which she was sent to an orthopaedic clinic, where they could not find anything wrong with Anna. At the hospital, the family talked about their concerns for Anna to a non-specialised psychologist, who said she might have autism and that she would take a look at her. During the evaluation, Anna was presented with a box of toys. Bente explained that the situation was a bit tense, something often pointed out by parents as affecting their children's behaviour and thereby the test result. Anna lifted up a Barbie doll and when the psychologist encouraged Anna, she also took a pair of boots for the doll, stamping it around a bit. In the rapport, it says, that Anna played with dolls. Bente got angry and told the psychologist that what Anna did was not 'playing', it was stamping things around, and she explained to the psychologist that Anna never had played with dolls at home. Bente tells her not to send the report to PPR. This was important for Bente, because, as she put it, it could be very dangerous if the PPR believed that her daughter could play with dolls since it would make it even harder to receive a diagnosis at a later time. At this point in time, Anna started to sniffle and roll her eyes and shoulders. They noticed this at the hospital and suggested to check her for epilepsy. Even though Anna did not get any attacks during the test and the parents reported that she could continue to sing while rolling her eyes and shoulders, the doctors concluded that she had epilepsy and put her on medication. A few years later Bente and Tom phased out this medication without this causing any problems for Anna, indicating, perhaps, that she had been diagnosed and put on medication too rapidly.

When Anna was six years old, she started in school. She was tested by a school psychologist, because she wet her pants several times a day. The psychologist did not find anything unusual except for her social skills, and the parents were told that since they already had one child with autism, Anna might also have 'something'. However, no further action was taken and Anna continued in her regular school. In her class there was a boy diagnosed with Asperger's syndrome, indicating that her immediate social surroundings were already duly configured to identify autism. But Bente was not sure. She had doubts regarding Anna's possible autism because Anna did not precisely fit the diagnostic criteria. Still, when she read about girls with autism, she recognized certain signs. Anna had difficul-

ties creating an overview of tasks and objects, including the toys in her room that she never play with. When she played it was with small toy animals and simple games that her mother thought were suitable for younger children. On the other hand, she had good intellectual skills and the first book she read was the bible. Also, Anna is good with math and the family has many anecdotes about Anna calculating the change during shopping. But at school, math can be difficult for her because of the way teaching is structured. For example, the narratives used to describe a mathematical problem are harder for her to understand than the actual calculations. This mode of teaching math does not make sense for her, as Bente puts it. The importance of things “making sense” is a common expression when trying to describe the psychology of people with autism. What “makes sense” separates people with autism from people without autism. Such signs, combined with the physical difficulties Anna faces, may seem an insufficient basis for suspecting autism. But the psychological difficulties could hide autism even if in a different way than Mads’ ADHD symptoms concealed it. Girls with autism are often described as invisible, silent or overlooked, both in scientific articles, by parents and at autism seminars, transforming »non-signs« or »insignificant signs« into signs in themselves. Fewer and less significant signs may be perceived as indexes for autism when interpreted by experienced parents like Bente and Tom. But as Bente explained, “it is hard - when are we seeing ghosts and when is the autism real enough? There is a thin line between knowledge and ghosts”. Bente was afraid that her knowledge about autism made her hyper-aware of behavior that could be wrongly interpreted as symptoms. At the same time, failure to act on a suspicion of autism could potentially harm her daughter. Bente knew that girls often received the diagnosis later in connection with comorbidity involving for instance eating disorders and self-harm. Therefore, she felt that she needed to keep an eye on her daughter and the potential signs of autism. Nevertheless, Anna was doing all right in school, she had friends, and as long as she was okay her parents did not want to press for a diagnosis.

Unlike the men in her family Anna’s problems seemed to relate to physical problems; she had hypermobile joints, she rolled both her eyes and shoulders and she sniffled, she wet her pants and was prematurely born. All these factors were simultaneously seen both as symptoms of and obstacles to receiving an autism diagnosis. Being premature placed her outside the category of so-called normal children and blurred the evaluation of her physical and mental capabilities at a given age. Pinto-Martin et al. (2011) point to low birth weight in prematurely born babies as a risk factor for autism. At the same time, prematurely born children

pose a challenge for screening children for autism because they are expected to have similar sensory, social and motor difficulties and benefit from routines and low stimulation. In Anna's case, a premature profile prevailed over an autism diagnosis. Another family interviewed by FLC also had a premature child and suspected autism. They experienced that a staff from the Danish Premature Society (Dansk Præmatur Forening) warned them not to seek an autism diagnosis because some children might outgrow their symptoms and thereby end up being misdiagnosed with autism, a diagnosis they were subsequently unable to get rid of. By definition, autism is something one cannot outgrow, in contrast to some of the problems seen in premature birth. There is a link between being premature and being autistic, but it is unclear whether a premature birth is a causative risk factor, or whether it is rather the similarity of symptoms that confounds the diagnostic epidemic. Either way, this overlay may contribute to our understanding of the configuration of the autism epidemic, since the percentage of preterm deliveries in Denmark had increased by 22% from 1995 to 2004, mirroring a global tendency (Langhoff-Roos et al., 2006).

Problems or profiles

The diagnosis of autism is closely linked to the understanding of the problems of the person in question. In the words of Aage Sinkbæk (2015)², the chairman of the Danish Autism and Asperger Association, nobody gets an autism diagnosis unless they have problems. Anna's problems did not directly relate to autism and were not interpreted as such. When she started to roll her eyes and shoulders, she was checked for epilepsy instead of autism. However, Anna's mother did not see her problems as purely physical since they resembled the tics Mads had and therefore could be classified as symptoms of autism. But Anna was just doing too well and was not perceived to have 'problems'. Socially she was more competent than her brother, which was even causing her mother to doubt a diagnosis. But perhaps Anna's social skills gave her other social problems than those normally associated with autism. Social problems like being unable to form and maintain friendships are one of the signs of autism (DSM5). Conversely, being able to form friendships causes doubts about autism as the right diagnosis. But when does a social problem get to be defined as such? Anna plays in ways that other children her age do not. This was one of the issues that caused frustration for her mother in relation to the psychologist that tested Anna's ability to play. They did not agree on how to define

successful play - is it enough to stamp things around? In cognitive tests, Bente was told that Anna stood out in connection with symptoms such as 'overlooking tasks', but that this could be explained by her premature birth. She had no need for social services, because she was doing well. The presence of a boy with autism in the classroom helped her since an autism-friendly environment was established which this enabled her to remain in her school.

Considering that girls with autism need to have social problems to get an autism diagnosis it is striking that girls are often understood as having 'profiles' instead of 'problems'. For example, Callesen (2013) has identified four types of autistic girls: 1) The passive/withdrawn; 2) The copying behaviour/sweet; 3) The arrogant/loner; and 4) The active/ADHD. These are personality types rather than areas of problems as established in the diagnostic criteria. The problems associated with these profiles are thought to be internalised and hidden, like misunderstanding social interaction in ways that cause stress, low self-esteem and depression. These distinctions are widely held by parents as explanatory models for understanding their child and the difficulties in identifying autistic girls. One important tool for uncovering autism in girls is the ADOS test that focuses on the social and communicative skills of the child. This test is created to match the understanding of social and communicative problems implied in the diagnostic criteria. Bente is worried that Anna's social skills will prevent her from being correctly diagnosed if she is not tested by experts in girl profiling. She wants her daughter to be checked in another municipality familiar with the special profiles for girls. The rigid boundaries between municipalities that are created by public funding mechanisms is another element of the configuration of autism that has gendered implications. With Tom's story in mind it is not difficult to understand why the family hesitates to fight this battle.

Configuring autism differently for boys and girls in this way may help us understand why girls with autism have a higher prevalence of comorbidity and misdiagnosis than boys. According to an investigation carried out by the Danish Autism Association (2014) the most common comorbidity among girls with autism was anxiety (43%), depression (41%), sleeping disorders (38%) and ADHD (26%). Anna's parents were aware of the challenges of diagnosing autism in girls. That Anna had not received a diagnosis was not enough for them to abandon their suspicion that she might have autism. Her problems did not precisely fit the diagnostic criteria for autism but other problems like wetting her pants and rolling her eyes were perceived as potentially autism-related. Anna had become one of the »ghosts« that parents are aware of but that do not have a formal diagnosis.

Configuring autism

The configuration of autism carves out boundaries between normal children and those in need of a diagnosis. Brinkman (2010) has described the danger of 'making the so-called normal ill' and described the Danish society as a "society of diagnoses", where we have become less inclined to accept that life is hard without using therapy and medicine to handle it, but also that the expectations to the individual have become more difficult to satisfy. The individual must be creative, innovative and ready for changes. Those who are not, stick out and may eventually have 'problems'.

In this landscape, we have seen how institutions and social networks play a crucial role in configuring the diagnostic process in a particular way that facilitates diagnoses under certain conditions and not under others. The configuration is highly gendered in favour of diagnosing boys rather than girls. Girls with autism who are not diagnosed do not receive the help that they may need. In the words of Bente: "We don't want to press it too much, she [Anna] shouldn't get a diagnosis just for the sake of having it." According to her mother, Anna should only receive a diagnosis if it helps her. Pursuing a diagnosis for Anna requires parental resources and there should be some hope that this investment of time and energy pays back in the form of increased wellbeing for Anna and her family.

The family of Bente, Tom, Mads and Anna show three different cases of autism. They are complex stories about the motivation and interpretations of an autism diagnosis. We have argued that their diagnostic process and their meetings with professionals in different settings illustrate important characteristics of the configuration of autism in Denmark, and here we have focused on the diagnostic properties of this configuration. By focusing on the configuration of diagnoses we have demonstrated that 'autism' cannot be meaningfully isolated to a mental condition 'inside the head' of individuals, but it must be seen as a complex dynamic between families, their networks and the institutions that monitor normal behaviour – in this case the infant and child healthcare programmes, the childcare services, the primary education institutions, the primary, secondary and tertiary healthcare sectors and the municipal authorities. It is in this configuration that girls with autism are perceived differently from boys with autism, and it is in this configuration that we must seek an understanding of the autism epidemic.

Noter

¹ Their names have been changed.

² Oral presentation at a seminar on autism and intervention at Aarhus University, 25 November 2015

Referencer

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing. <https://doi.org/10.1176/appi.books.9780890425596>
- Andersen, L. B. (2007). Autisme og piger – en særlig diagnostisk udfordring. *Autismebladet*, nr. 1, 12-24
- B. Robinson, E. et al. (2013). Examining and interpreting the female protective effect against autistic behavior. *PNAS* vol 110, nr 13. <https://doi.org/10.1073/pnas.1211070110>
- Bearman, P. S. et al (2010). Social Influence and the Autism Epidemic. *AJS* Volume 115 Number 5, 1387-1434
- Bernard, S. (2004). Association between Thimerosal-Containing Vaccine and Autism. *Journal of the American Medical Association* 291, 180
- Brinkmann, S. (2010). *Det diagnosticerede liv : sygdom uden grænser*. Klim
- Vidensråd for forbyggelse (2014). *Børn og unges mentale helbred. Forekomst af psykiske symptomer og lidelser og mulige forebyggelsesindsatser*
- Callesen, K. (2013). *Piger og autisme – i praksis*. Landsforeningen Autisme. Psykologisk Resource Center. <http://www.autismeforening.dk/log/Piger%20med%20autisme%20SIKON%202013.pdf>
- Center for Disease Control and Prevention, *ICD-10-CM Official Guidelines for Coding and Reporting*, 2015, <http://www.cdc.gov/nchs/icd/icd10cm.htm>
- Christoffersen, Mogens N., Højen-Sørnsen, Anna-Katharina and Laugesen, Laura (2014). *Daginstitutionens betydning for børns udvikling. En forskningsoversigt*. SFI – Det Nationale Forskningscenter for Velfærd.
- Det Etisk Råd (2016). *Kernetekst 1: Diagnosen som det bedste og det værste*.
- Dilley, R. (1999). *Introduction: The problem of context*. In R. Dilley (Ed.). New York: Berghahn Books.
- Dworzynski, K. et al. *J. Am. Acad. Child Adolesc. Psychiatry* 51, (2012).
- Eyal, G. (2010). *The Autism Matrix*. Cambridge: Polity Press
- Eyal, G. (2013). For a Sociology of Expertise: The Social Origins of the Autism Epidemic. *The Journal of Sociology*, Vol. 118, No. 4, pp. 863-907. <https://doi.org/10.1086/668448>
- Grinker, R. (2009). *Isabel's world: autism and the making of a modern epidemic*. Thriplow: Icon
- Houston, R. & Frith, U. (2000). *Autism in History: The Case of Hugh Blair of Borgue*. Blackwell: Malden
- Jennifer, A. Pinto-Martin et al. (2011). Prevalence of Autism Spectrum Disorder in Adolescents Born Weighing less than 2000 Grams. *Pediatrics*. Nov; 128 (5)

- Kopp, S. & Gillberg, C. (1992). Girls with social deficits and learning problems: Autism, atypical Asperger syndrome or a variant of these conditions. *European Child & Adolescent Psychiatry*, Vol. 1, Issue 2, 89-99. <https://doi.org/10.1007/BF02091791>
- Landsforeningen for Autisme (2014). *Autismebladet – Piger bliver til kvinder med autisme*. Nr. 9
- Langhoff-Roos, J., Kesmodel, U., Jacobsson, B., Rasmussen, S., & Vogel, I. (2006). Spontaneous preterm delivery in primiparous women at low risk in Denmark: population based study. *BMJ*, 332, 937-939. <https://doi.org/10.1136/bmj.38751.524132.2F>
- McDermott, R. P. (1993). *The acquisition of a child by a learning disability. Understanding practice: Perspectives on Activity and Context*. Edited by Seth Chaiklin and Jean Lave. Cambridge University Press, pp. 269-305. <https://doi.org/10.1017/CBO9780511625510.011>
- Roberts, Eric M., Paul B. English, Judith K. Grether, Gayle C. Windham, Lucia Somberg and Craig Wolff. (2007). Maternal Residence Near Agricultural Pesticide Applications and Autism Spectrum Disorders among Children in the California Central Valley. *Environmental Health Perspectives*, 115 10, 1482–89.
- Rosenberg, C. E. (1992). *Explaining epidemics and other studies in the history of medicine*. Cambridge: Cambridge University Press. <https://doi.org/10.1017/CBO9780511666865>
- Skuse DH (2000). *Imprinting, the X-chromosome, and the male brain: Explaining sex differences in the liability to autism*. *Pediatr Res* 47 (1):9–16. <https://doi.org/10.1203/00006450-200001000-00006>
- Wing, L. (1981). Sex ratios in early childhood autism and related conditions. *Psychiatry Research*, 5. [https://doi.org/10.1016/0165-1781\(81\)90043-3](https://doi.org/10.1016/0165-1781(81)90043-3)