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How We Talk When We Talk About Disabled Children and Their Families:

An Invitation to Queer the Discourse

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Abstract

Despite contemporary perspectives in resource-oriented music therapy, community music therapy, and anti-oppressive practice, there seems still to be a tendency to describe disabled children and their families in a pathologizing, problem-focused way. Disability is often located within the child and not in the societal structures that sustain and support the concept of disability as tragedy and burden for the families. Queer theories challenge the concepts of normality and fixed identities, reject pathologization, and politicize access. In this paper, I attempt to explore how queer theories offer a critical perspective on normativity, identity, and power. I will do this by exploring the concepts of normality and normativity and discourse, current representations of disabled children in the music therapy literature and by reflecting upon an ongoing participatory action research project where I aim to co-create knowledge on musicking, its accessibility, and meaning together with disabled children and their families. I argue that we need to change the way we talk and write about our practice as well as to challenge the concepts and attitudes toward diversity in order to contribute to inclusive environments that appreciate and celebrate diversity.

Introduction

"No, we only have normal chairs," one mother I am working with heard when she asked about a chair for her baby, mentioning that her baby has Down syndrome[1]. But what are normal chairs and what are normal people and who makes up the rules about what´s normal and what´s not?

The starting point for this paper is a discomfort on how disabled children and their families are looked at and talked about – in everyday life situations, as in the example above, but also in educational contexts I worked in, and in the music therapy discourse. Contemporary perspectives in music therapy emphasize resources (Rolvsjord, 2010), fight for social justice (Vaillancourt, 2012), and take into account context, cul-
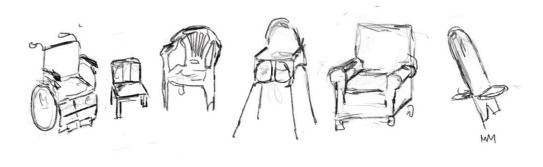
Figure 1.

What is a normal chair? Image description: A drawing of a wheelchair, a chair with a shorter leg, a plastic garden chair, a high chair, an arm chair, and an African chair.

ture, and politics (Pavlicevic & Ansdell, 2004; Stige & Aarø, 2012). However, and not doing justice to the literature that indeed does the contrary, there is a tendency to represent disabled children and their families not in terms of their resources and their social and cultural context, but in terms of their difficulties and often based on the child's individual mind-body differences. The aim of this paper is to deliberately challenge the current discourse on disabled children and their families and the conceptualization of music therapy's role in context of disability.

The recognition of the social, psychological, and political dimension of discourse, is often traced back to the influence of Michel Foucault, a key queer theorist. Foucault (1981) described discourse as the social system of producing knowledge and meaning in society. He defined discourses as "practices which systematically form the objects of which they speak" (1972, p. 49). This means that discourse is active – we produce things through language. So, if we communicate about children in a deficit-oriented way, we make meaning of them in a deficit-oriented way and tell the world that this is the way we should conceptualize disabled children and contribute to the system that disables them. And while those practices belong to collectives instead of individuals, they have an impact on the individual as the discourse constructs them (Bührmann et al., 2007).

Queer theories[2] challenge the concept of normalcy and normativity, and this is why I explore queer theory as a critical perspective to inform discourse about disabled children. My curiosity in queer theory came from an introduction within disability studies. Queer theories, as I understand them and deploy them, are both methodology and ontology. They call to challenge all kinds of normative understandings of identity and their oppression. Queering music therapy in context of disabled children destabilizes established ideas, countering music therapy approaches that aim at cure or normalization of difference.

The social context where I am writing this from is Bergen, Western Norway. While Norway is a country that is ranked high in terms of democracy, civil and political

rights, and freedom of expression, both queer and disabled people experience exclusion.[3] While acknowledging the fluidity and temporality of identities, the position I write from is a privileged one as a white, cisgender, straight, non-disabled woman. My own educational background is in music therapy and what often is called "special education," which is a problematic notion I will later return to. Through an interest in critical education, I explored disability studies, a field that has captured most of my attention since. However, similar to queer theory, disability studies critiques the foundations of music therapy. From my view, taking such critique serious is vital for the further development of music therapy as an anti-oppressive approach. Butler asserted in an interview with Salih (Butler & Salih, 2004) that critique is about

> opening up the possibility of questioning what our assumptions are and somehow encouraging us to live in the anxiety of that questioning without closing it down too quickly. Of course, it's not for the sake of anxiety one should do it…but because anxiety accompanies something like the witnessing of new possibilities (p. 331)

In this sense, questioning how we communicate as a profession is a way of developing more knowledge and, therefore, offers the development of new possibilities.

The first part of this paper gives a short background to the overlaps of queer theory and disability studies and explores the concepts of normalcy and normativity. With this as a background, dominant discourses about disabled children and their families and current representations of disabled children in the music therapy literature will be examined. I will present my own current research project and discuss how I engage with issues of power and language there. The last part of the article discusses how we talk, how we could talk instead, and what that would mean.

Queer theory meets disability studies meets music therapy

Queer theories and disability studies are two separate fields which are also interwoven through their historical link to critical theory, sharing key theorists and challenging hegemonic constructs of normalcy. By emphasizing the experiences of those who experience discrimination, violence, and intolerance, both fields: reject pathologization, politize access, and problematize concepts of difference and norms, which marginalize people who do not conform. Theoretically, both fields draw upon the concept of the 'other,' a constructionist approach to identity and challenge binary oppositions, as for instance non-disabled-disabled or straight-gay (Sherry, 2004).

Disabled and queer people experience forms of exclusion that mark them as "other," as different from the white, heterosexual, non-disabled, cisgender man. While queer and disabled experiences might have communalities, both categories are fluid categories. "The other" has been considered within feminist theory and refers to the concept of thinking about people that are different from oneself. For Wendell (1996), the symbolic meaning of disability and/or illness (e.g. weakness, imperfection, pain) contributes to the production of "the other," and these symbolic meanings are, at the same time, its product. I see this related to Focault´s argument that people create the objects by speaking about them. Wendell (1996) called this for a self-perpetuating system where the exclusion of disabled people prevents society from structuring itself for a diversity of ability. The concept of "the other" is therefore closely linked to the hegemonic construct of normalcy.

A critique of hegemonic normalcy has been central to both fields. Within disability studies, disability can be understood as a disruption of normalcy, making assumptions visible, which then allows for questioning how normalcy was constructed in the first place (Titchkosky & Michalko, 2009). A central concept linked to normativity in disability studies is that of the "normate," which Garland-Thomson (1997) described as "the social figure through which people can represent themselves as definitive human beings" (https://keywords.nyupress.org/disability-studies/works_cited/garland-thomson-rosemarie-se-2/). Similarly, Davis (1995) wrote: the "problem" is not the person

with disabilities; the problem is the way that normalcy is constructed to create the "problem" of the disabled person" (p. 24).

Autistic activist Amy Sequenzia (2016) stated: "We are not allowed to simply be. Being 'normal' is the goal. When we cannot 'be normal' we should, at least, 'act normal'. If we don't or can't, we are failures, not good enough" (n.p.). Ableism has a similar function as cisgenderism and heterosexism, as well as other systems of oppression. Disability studies scholar Campbell (2001) defined ableism as:

> […] a network of beliefs, processes, and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human (p. 44).

Queer theory meets disability studies also more literally within cripqueer theory and neuroqueerness. Cripping, similar to queering, reframes and reinterprets representations of disability (Ramlow, 2009). Walker (2014) offered the following definition:

> Neuroqueer is both a verb and an adjective. As a verb, it refers to a broad range of interrelated practices. As an adjective, it describes things that are associated with those practices or that result from those practices: neuroqueer theory, neuroqueer perspectives, neuroqueer narratives, neuroqueer literature, neuroqueer art, neuroqueer culture, neuroqueer community. And as an adjective, neuroqueer can also serve as a label of social identity, just like such labels as queer, gay, lesbian, straight, black, white, hapa, Deaf, or Autistic (to name just a small sampling) (n.p.).

While describing neuroqueer in this way, Walker emphasized that this is not an authoritative definition as people who identify as neuroqueer could subvert any definition.

Both queer and disability theorists point to the possibilities and potentials that (neuro)queering provides. For McRuer and Wilkerson (2003) "another world can exist in which an incredible variety of minds are valued" (p.14). Similarly, Ramlow (2009) described the coalition of queer theory and crip theory as "world-(re)making." Goodley and Runswick-Cole (2010) suggested that disabled children can be understood as queer children: "with the potential to subvert, rethink and reject normative, narrow, dull, limiting, disablist, respectable, middle of the road, conservative, traditional and exclusionary schools, classrooms and pedagogical practice" (p. 275).

Considering this, where do queer theory, disability studies, and music therapy meet? While there are different possibilities for where these theories might meet with the field of music therapy, I will focus on the concepts of normality and normativity.

Disability scholars have criticized music therapy as supporting the medical model of disability and contributing to oppression. Straus (2011), with reference to the American Music Therapy Association's definition of music therapy, concluded "music therapy is a normalizing enterprise, bound up with the medicalization and remediation of disability" (p.158).

Straus (2014) further argued that, 'normative music therapy': "accepts that many sorts of human variability should be understood as illnesses, diseases, or other sorts of pathological medical conditions, and offers music as a source of normalization, remediation, and therapy toward a possible cure" (n.p.). However, as Straus pointed out, for many conditions this is neither possible nor desirable. For Straus, music therapists can't and shouldn't aim at curing or normalizing; instead, they can provide spaces for shared pleasure through mutual music making, for enhancing their indigenous culture, and an avenue for self-expression, self-realization, and knowledge. Relatedly, Cameron (2014) stated, "It is not that I believe music therapists are not good or well-intentioned people but that, in supporting a medicalising, individualising, normalising ideology, I believe they are complicit in the oppression of the very people they intend to help". In my view, Straus and Cameron might not do justice to the variety of music therapy approaches, but they do provide an important perspective here, which is how music therapy discourse is perceived as normalizing by two disabled scholars.

Within music therapy, the focus on normativity has been growing throughout the last few years. Rolvsjord and Hadley (2016) stated, "[o]ne of the crucial steps in contesting hegemony is learning to recognize one's relative position in the system and unmasking power relationships, whether they manifest in class oppression, sexism, racism, ableism, or heterosexism" (p. 477). Fairchild and Bibb (2016) published a call to action regarding the representation of people in music therapy research and practice. They asked whether the problem-focused language is in line with the strength-based way music therapists work and argue for a better balance in discourse. Bain, Grzanka, and Crowe (2016) pointed out how a conceptual model of queer music therapy can emphasize opportunities for empowerment, as opposed to 'fixing' LGBTQ people, and can encourage the challenging of oppression instead of suggesting that people assimilate. They pointed to the etic of radical inclusivity, "in which structures are critiqued for how they subtly reinforce oppression so as to make environments safe and accepting of human cultural diversity" (p. 24).

Dominant discourses and current representations of disabled children and their families in the music therapy literature

Ansdell (2003) and Rolvsjord (2010) have emphasized that the discourse of music therapy matters as it informs our practice and thinking. How we communicate about practice influences not only how we understand our practice, but also the broader system (Rolvsjord, 2010). This will contribute to either stabilization or destabilization of certain values. Ansdell (2003) stated that "As a discourse, music therapy is not something discovered 'outside' language and subsequently described 'inside' language, but something actively constructed in and through language" (p. 154).

Music therapy in context of disabled children and their families doesn't occur within a vacuum but instead within professional contexts that are based on their own ideologies and frameworks of understandings. Music therapy with children and their families often occurs within either educational or health settings. From a disability studies perspective, the dominant discourse on families of children with disabilities is strongly influenced by the medical model and based on assumptions of grief and tragedy (Lalvani & Polvere, 2013). Disabled children and their families continue to experience marginalization, battles with the welfare system, and negative attitudes. There is still a focus on the burden of having a disabled child, which is a medicalized understanding that positions disability as a personal and family tragedy and aims to provide aid for families to cope better with the burden of the tragedy. However, what families describe as the 'real burden' are the battles they fight for social care and health services (McLaughlin, Coleman-Fountain & Clavering, 2016). Ryan and Runswick-Cole (2008) argued that positive or even neutral family experiences still remain under-represented.

In my efforts to get an overview on how disabled children and their families are described in music therapy literature, I completed a Boolean search and looked at articles published from January to December 2018. I searched for the terms *disability*, *disabled*, *special needs*, *inclusion*, *developmental delay*, *autism*, *neurodiversity*) within the *Journal of Music Therapy*, *Nordic Journal of Music Therapy*, *Voices: A World Forum for Music Therapy*, and *Approaches: An Interdisciplinary Journal of Music Therapy*.

While this has by no means been a comprehensive review, I found three examples of representations of disabled children and their families within music therapy literature. This is a very small sample, however, the range of approaching disabled children was interesting and might to some degree be representative. One of the articles would be clearly located within the medical model/special education model from the perspective taken here. Yoo and Kim (2018) research the relationship between dyadic drumming and the improvement of social skills. They use medical model terminology (i.e., autism spectrum disorder, intervention, high-functioning, mild symptoms) and understand disability as intrinsic to the individual: "[c]hildren with autism spectrum disorder (ASD) show atypical development or persistent deficits in social skills (p. 341). Yoo

and Kim want to "improve function among children with ASD" (p. 343) and the aim could therefore be understood as linked to normalization.

In the article of Stensæth (2018), there are some tensions between a focus on access, participation and quality of life, and language and approaches that are not fully aligned with that focus. Stensæth (2018) discussed aspects of subject-interaction between the participants of the RHYME project (disabled children between 7 and 15 and their families) and interactive musical media. Health was conceptualized as "a fluid state that can be influenced by addressing another person by engaging in musical actions with that person and with the help of objects" (p. 313). In contrast to that fluid health definition, disability seems to be something more fixed, represented though ableist categories (e.g., "mental age," "poor (or absent) verbal language," and linking "behavioural style" with "disability condition"). Disabled children are however conceptualized as co-creators within the project and therefore as having expertise.

Turry´s (2018) article reflected, for me, a different worldview and could be located within a social/affirmative model perspective. Turry, with reference to Silverman (2015), called the approach to autism taken by the researchers of the TIME-A study (Gold and Bieleninik, 2018) as outdated. Turry argued that future studies should focus on the question of, "How does increased musical engagement lead to overall improvement in the child´s life?" Turry further suggested that researchers should collaborate with autistic advocates in efforts to ensure that the research questions and outcome measures are in line with contemporary approaches. Here, it seems that Turry doesn´t necessarily criticize the randomized controlled trial methodology but asks us to shift frames.

How do we talk when we talk about disabled children? Although the aforementioned are only some examples of discourse regarding disabled children and are therefore not necessarily representative of all discourse, they give an idea of current understandings and current developments. At the European Congress in Aalborg this year there was a similar diversity of approaches – music therapists locating disability within the individual, music therapists focusing on individual challenges in context, music therapists describing social justice approaches, but using pathologizing language and music therapists discussing the notion of neurodiversity[4]. As pointed out above, discourse is linked to the broader surrounding system. Music therapists live, work, and get funding from places with different worldviews. I will therefore in the next section turn to my own work, attempting to make some of the complexity of discourse in context visible.

Reflections on issues of power and discourse in an ongoing research project with disabled children and their families

Now, I will present some reflections on my own work—not to situate my own work as a good example for radically inclusive practice but to instead share how I have been engaging with and challenging issues of discourse and power relations. The "music café" is an ongoing project connected to my Ph.D. which explores musicking and its accessibility and meaning through a weekly social musical meeting space together with families with disabled children between 0 and 3. The project is informed by both community music therapy tradition and the methodological approaches of participatory action research, emancipatory disability research, and ethnography.

Terminology is a tricky part of my project. Through my interest in disability studies and political perspectives on disability, I have been using identity-first language and find the notion of "special needs" uncomfortable to use. However, person-first language is what is most commonly used in Norway. For both parents and professionals "disabled child" can be perceived as pathologizing, outdated language. I therefore had to find a way to manoeuvre between my own interest in representing children in a way I consider respectful and being able to communicate and be understood by both parents and other professionals. I realized, through experience, that this is a difficult endeavour. I tried to recruit families "with needs for adaptations" (this is an English

Figure 2.

Representing the music café. Image description: A drawing of a group of people sitting in a circle on a floor.

translation which sounds more intelligible in Norwegian) to bypass the discussion regarding person- or identity-first language. However, it seemed very unclear for people who that project was directed at and whether their needs were too small or too great. For me, this shows how language is linked to our social context and that we need to take our own context into account if we want to reach the people we want to work together with.

Within this project, different ways of perceiving and communicating are a source of knowledge for exploring when, how, and for whom music becomes accessible. The project builds on the idea that music therapists, with their skills on how to make music and its affordances accessible, and neurodiverse families, with their insights on their needs and interests, can benefit from researching music's accessibility in collaboration. One focus of the project is to develop practical resources that can be relevant for the participating families but also for other families. As the aim is to create resources (such as song cards) that are relevant and useful for all family members, everyone has an equally important expertise. So, while it might be most important for the parentto have the lyrics and sign language visible, it might be the tactile symbol that is most important for the child. I have presented on my project at international congresses twice and both times received the same question: But what is the goal for the children? While this might also point to my own lack of clarity, such questions seem linked to expectations for what a music therapist must be doing when working together with disabled children. The idea that the families themselves can set the goals, that having a good time, connecting with other families, and learning more about how to use music together are valid goals and that a child's choice on the design of a song card is a relevant and important contribution seems to be challenging for some individuals.

The focus on accessibility and the children´s competence in this project was intentional in order to put the children in a position of power. However, in practice, parents seem accustomed to responding to questions on behalf of their children (especially if the children communicate non-verbally). In some moments, this might be the right thing to do, as it might be part of the parent´s expertise and amplify the child´s voice. In other moments, however, this might take away the possibility for the child to give a different response than expected by the parents. Therefore, balancing everyone's par-
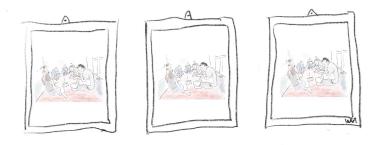
Figure 3.

Shifting frames. Image description: Three frames in a line with the same drawing of a group of people as in figure 2 inside.

ticipation in decision-making processes needs ongoing negotiations and continues to be challenging. Video recording every music session is therefore an important tool, as we can go back and look at situations where there was a response from a child I/we didn't understand and then can amplify the child's voice. The decision to focus on the video material also links to the conviction that that all family members needs to be equally represented. In order to allow for the expertise of the children to be brought into awareness, I bring materials to make new song cards and present them to the children and give them choices. We can then observe their response and engagement and create resources based on their preferences.

«Sounds like I am the expert» said the parent from the pilot project that I conducted for the current project when we watched a video clip where they came up with a really good idea. However, they clearly didn't feel like that this was true. To try to develop a space where power and expertise is shared has therefore become an important focus of the music café and I want to share an example of how that looks like. I asked a mother that recently joined the project whether there was something she thought we could do differently to make it easier for the child to join, and she couldn´t think of anything in that moment. However, the next week, she said, "You asked if there was something we could do differently, and I think we need to sing faster. I don´t think [my child] recognized "The itsy bitsy spider" last time." The mother also shared, that at home, they were singing it three times, also adding a "giant" spider and a "very tiny" spider. We did that later in the session, doing big movement and tiny movements. The child showed with smiles and attention how much this version of "the itsy bitsy spider" was appreciated and it turned out that this was much more engaging for everyone involved. People have various experiences and competencies in making music that are very valuable in music therapy and should be taken into account.

Shifting frames

Music therapy has been conceptualized as a disabling practice, aligned with the medical model aiming at normalizing (Cameron, 2014; Straus, 2014). Music therapists have also claimed, though, that music therapy is about making music accessible and celebrating diversity (Shiloh & LaGasse, 2014) . Queering is about challenging binaries and taking complexity into account and is therefore both a useful and necessary perspective, given that music therapy is probably both disabling and celebrating diversity and everything in between for different people in different contexts.

According to Foucault (1985), to problematize is "an endeavor to know how and to what extent it might be possible to think differently, instead of legitimizing what is already known" (p. 9).What would it mean to resist ableist understandings in music therapy? Would we lose something if we were to conceptualize therapy differently? In figure 3, you see three different frames. You see exactly the same picture within each frame, but we can both talk about and make sense about what you see in very different manners. If my frame is social justice, my narrative will be a totally different one than if my frame is normalizing. In my view, it is fruitful to ask which frame we are using and why we are doing it. While working in a "special" education context or at a rehabilitation unit, for example, we will need to communicate in a way professionals we are working with can understand. However, considering that discourse co-constructs reality, it matters how we do it, and I argue that we can represent children in respectful ways without pathologizing differences in any context.

Foucault (1977) stated, "(t)he judges of normality are present everywhere. We are in the society of the teacher–judge, the doctor–judge, the educator–judge, the 'social worker'–judge; it is on them that the universal reign of the normative is based; and each individual, wherever he [she, they] may find himself, subjects to it his [her, their] body, his [her, their] gestures, his behaviours, his [her, their] attitudes, his [her, their] achievements". (p. 304). What can we do to avoid being a "music therapist –judge of normality"? Queer theory might help us to think and act differently by questioning how we construct normalcy and difference in the first place. Dismantling ableism might be a vital part of that process. As activist Human (2017) pointed out, we can work on our ableism, but everyone must make an effort "to learn about disability issues and to examine and confront ableist bias in ourselves and our communities. We all have a duty to understand and combat ableism" (n.p). And I would add that music therapists with privileged identities (particularly non-disabled music therapists) need to acknowledge those identities (Hadley, 2013).

Analogous to the rejection of superficial efforts for inclusion by simply inviting LGBTQ+ individuals to an existing historically cisgenderist[5] and heterosexist therapeutic space (Boggan, Grzanka, & Bain, 2017), it is not enough to invite people into a historically ableist therapeutic space. We need not only to reflect about how we communicate and how we make sense of our work, but also about whose voices are heard. There is now a considerable number of both queer and disabled/autistic music therapists (see the Facebook group "Music Therapy and the Autism Spectrum", the Facebook groups of disabled and queer music therapists, and the PhD thesis of Shaw, 2019) that we should listen carefully to. There are also self-advocates, such as Thatcher (2016), an autistic mother of autistic children, who wrote an "autistic family approach to therapy" consisting of 12 points including these four:

> 1. We embrace the Neurodiversity Paradigm. We view being autistic as a valid way of being and reject any therapy which pathologizes autism,
>
> 3. Focus on communication not just spoken language. This includes all forms of AAC and Facilitated Communication
>
> 5. Requests for eye contact or positive reinforcement for eye contact given is disrespectful and strictly forbidden, and
>
> 9. Under no circumstances should there be attempts to extinguish or discourage "autistic behaviors". This includes stimming, flapping and scripting (n.p.)

These guidelines both challenge and support music therapy practice, depending on the frame taken. I argue that we also need to provide opportunities for disabled children to shape music therapy with their perspectives, their discourse, and their needs. This should occur both in everyday practice and by researching together with children, amplifying their voices and co-creating an approach to music therapy that acknowledges the fluidity of identities and strives for social justice. Several authors cited above pointed to the (world re-making) potential of neuroqueering and especially the potential of disabled children to challenge normative and exclusionary thinking and practice. From my point of view, this perspective forms an invitation and, at the same point, emphasizes that queering the discourse is not (only) about terminology but about co-creating different structures.

To queer the discourse might also mean to question underlying assumptions and to make the links between power, knowledge, and discourse visible. If we strive for the field to move towards anti-oppressive, social justice-oriented approaches, we need to challenge, question, and reframe. Therefore, the invitation here is to question our work, to listen to disabled people and especially children, to reflect upon how we present our work and the people we work with, and to testnon-normative frames.

About the author

Maren is a PhD student at Nordoff Robbins/Goldsmiths, University of London and works currently at GAMUT, University of Bergen/NORCE. She is passionate about working together with children and families and has an interest in disability studies, emancipatory research and community music therapy. In her PhD, she explores together with families how, when and for whom musicking becomes accessible.

Notes

1. While I throughout the article use identity first language, I follow here the preferred language of people with Down syndrome see for instance here: https://nnds.no/2019/03/20/jeg-er-ikke-en-diagnose-jeg-er-marte-helt-unik-som-alle/

2. I use queer theory in plural to emphasize the diversity of approaches included.

3. Two recent examples: On the 8th of June the Bergen Pride took place, but as Helle, a 'wheelchair activist' pointed out, activities are not accessible for wheelchair users. Another recent example is Erle and her family who fight for Erle's right to be with her family and not in an institution where she currently needs to sleep due to complicated epilepsy (https://www.altaposten.no/nyheter/2019/05/29/Erle-f%C3%A5r-BPA-%E2%80%93-Gle-den-er-ubeskrivelig-19144957.ece).

4. See the book of abstracts here: http://people.hum.aau.dk/~hanne/EMTC19%20AB-STRACTS.pdf.

5. Cisgenderism and cissexism are often used interchangeably.

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