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Nordic Journal of
MEDIA STUDIES

Influencing through advocacy

Parents of children with disability giving and seeking support on Instagram

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ABSTRACT
In this article, I examine how parents raising children with disabilities are using Instagram to advocate for the rights of their children, and how these practices can be understood as a form of non-commercial influencing. I study how these practices enable the creation of supportive networks as the basis of performing advocacy regarding disability rights. Based on interviews with six mothers who use Instagram to share insights from their everyday lives, the analysis explores how their content curation and network building provides support and enables advocacy with the purpose of influencing public opinions about disability. Despite lacking commercial interests, their sustained engagement, storytelling, and ability to mobilise audiences position them as influencers within the online disability community.

KEYWORDS: parents, influencers, children with disability, online advocacy, discourses of disability

Introduction

Images of children often make compelling content on social media. Like adorable kittens and mouth-watering food videos, platforms such as Instagram and TikTok are awash with videos of children engaging in amusing antics, saying funny things, or simply being their charming, unpredictable selves. This phenomenon, known as sharenting, has evolved significantly (Abidin, 2017; Damkjær,

Johansen, S. L. (2025). Influencing through advocacy: Parents of children with disability giving and seeking support on Instagram. *Nordic Journal of Media Studies*, *7*(1), 112–129.
https://doi.org/10.2478/njms-2025-0007

2018; Jorge et al., 2022; Ruiz-Gomez et al., 2024). Once a way for parents to share family moments with friends and relatives, it has become, for some, a professional endeavour. Sharing content about their children has turned into a source of income for certain individuals, with influencer profiles transforming into carefully curated channels aimed at gaining followers, sponsors, and brands.

While influencers are most often defined by their commercial interests (e.g., sponsored content, etc.), other social media users utilise their online presence to advocate for social or political causes. One such group is parents of children with disabilities. These parents use social media not just to document their journey and to connect with people in similar situations, but also to advocate for awareness regarding both general and specific aspects of everyday life and well-being of children with disabilities. At the same time, they build communities for those who might otherwise feel isolated. As Helle, a mother of a child with disabilities, expressed: "Because when I put down the phone, I don't know anyone who has a child with a disability. So, you feel incredibly alone and suddenly very much like an outsider in some way". This quote highlights the isolation many such parents feel, and, as I explore in this article, the sense of community experienced through social media platforms that form the basis of influencing practices to raise awareness, visibility, and advocacy for children with disabilities. These practices, I argue, can be understood as influencing, albeit without commercial interests.

Purpose of the study

In this article I aim to delve deeper into the utilisation of social media by parents of children with disabilities, exploring both their motivations and the impact of their online presence. At the core of the analysis is how these parents are influencing through advocacy and how they are building on personal storytelling and community mobilisation to raise awareness and positively impact public opinions around disability. Through an empirical interview study, I seek to provide insight into the experiences of parents who, despite facing unique challenges, find themselves drawn to the online world for connection, advocacy, and the opportunity to speak up on behalf of a group of citizens – children with disabilities – who are not able to do so themselves. I highlight the dual nature of social media as both a platform for community-building and a space where complex issues of privacy, comparison, and representation come to the forefront and discuss how this enables influencing through advocacy. In doing so, I aim to offer a nuanced understanding of how social media serve as a tool for support and empowerment, while also reflecting on the complexities and contradictions inherent in the act of sharing one's life, and one's child's life, in a public forum.

I aim to bring nuance to the concept of influencers by focusing on how these parents not only share and engage with people in similar situations but also take part in current debates about the living circumstances of people with disabilities in the Danish welfare society. Furthermore, they use their platform to inform and educate the public, and in some cases also welfare professionals, about the everyday struggles of their children.

Previous research: Advocacy between parenting and politics

With the aim of expanding the understanding of influencers and influencing, I draw on a theoretical framework related to influencer culture. More precisely, the analysis is positioned between studies of parent influencers and political influencers. The article presents an empirical examination of the everyday experiences of parents who unexpectedly find themselves in situations they never anticipated and who, in most cases, never intended to use social media (specifically Instagram) as a primary means of connecting beyond their households, or to advocate for and raise awareness of their (and their children's) life circumstances. Consequently, these two types of influencer practices provide a relevant backdrop for the article.

A common denominator across all influencer practices is authenticity. Audiences engage with otherwise unknown individuals on social media platforms because they find them relatable, and authenticity is the most valued currency in these relationships (e.g., Arriagada & Bishop, 2021; Hendry et al., 2021). In a contemporary and increasingly professionalised platform economy, authenticity is becoming more and more an "intentional strategy, rather than a generic quality" (Arriagada & Bishop, 2021: 572). At the same time, authenticity is strongly connected to influencers presenting themselves as "real" human beings, communicating "failure, pressure, depression, tears, vulnerability" (Banet-Weiser, 2021: 143).

Parent influencers

As mentioned, the practice of parents creating social media content centred on their children has become a contentious issue (Holiday et al., 2020; Blum-Ross & Livingstone, 2017; Ouvrein, 2024). Beukels and De Wolf (2024), in their systematic review of parent influencers, highlighted how this phenomenon reflects broader societal trends and neoliberal ideologies that shape both parenting and employment. Parent influencers uniquely blend the roles of parents, advertisers, and influencers, balancing self-expression, professionalisation, and authenticity. They carefully manage their personas to remain relatable yet polished, while their social involvement often leads them to provide support, foster community, and challenge societal norms.

This practice can be understood through the concept of sharenting (Abidin, 2017; Damkjær, 2018; Jorge et al., 2022; Ruiz-Gomez et al., 2024), which refers to the sharing of texts and images of or about children not only with close friends and family but with a broader public audience. Sharenting draws upon characteristics of earlier "mommy blogging" (Petersen, 2015), which has since evolved into a dominant content genre on social media. Research often critiques sharenting for its negative implications, addressing immediate concerns such as sharing identifiable images of children, as well as subtler issues like data collec-

tion and the commercial exploitation inherent in social media platforms. Leaver (2020) has discussed how sharenting practices have become normalised, noting trends like the use of hashtags such as #ultrasound to share prenatal images. He introduced the concept of "privacy stewardship", advocating for a more mindful and ethical approach to managing children's digital footprints.

In the following, I present and reflect on research related to, first, parent influencers and sharenting practices, and second, the representation and advocacy in relation to children with disabilities. Only a few studies have focused specifically on the practices and reflections of parent influencers whose children have disabilities; exceptions can be found in the work of Blum-Ross and Livingstone (2017) and Jorge and colleagues (2022). Similarly, Ruiz-Gomez and colleagues (2024) have analysed a profile where parents share images of their child with Down's syndrome. In their study, Jorge and colleagues (2022) discussed how mommy influencers in Portugal navigate the complexities of motherhood and work through social media, promoting a neoliberal ethos that emphasises individual solutions to family challenges. Through a qualitative study of eleven influencers, the study reveals how they share personal experiences while balancing emotional labour and consumerism. Influencers often transition from traditional jobs to monetise their online presence, reflecting economic pressures and the need for flexibility. Their narratives intertwine emotional and material aspects of motherhood, showcasing relatable struggles and aspirational lifestyles, ultimately shaping public perceptions of parenting in a post-austerity context. Ruiz-Gomez and colleagues (2024) have investigated the use of social media for advocating for children with disabilities, focusing on a British girl with Down's syndrome. Their findings highlight how such advocacy can foster community growth, challenge social stereotypes, and promote inclusion. However, the study also raises significant concerns about issues of privacy, commodification, and the limitations of self-representation. Furthermore, their case study underscores the challenges in ensuring authentic self-advocacy for disabled children, as parental perspectives may not fully represent the child's voice or agency.

Studies as those presented above underscore the potential of social media as a tool for advocacy, providing spaces for people with disabilities to shape narratives and raise awareness. However, scholars have also raised concerns about how children may perceive and react to the sharing of their childhood images in the future. Leaver (2020) and Blum-Ross and Livingstone (2017) have emphasised the importance of a collaborative approach, where parents and children "partner up" to ensure children's rights are respected online. Goggin and Ellis (2020) examined the complex interplay between data privacy, social media, and the representation of children with disabilities. Using sharenting as an example, they highlighted tensions between privacy, data exploitation, and advocacy, noting that children with disabilities often lack a voice in these discussions. Similarly, Neag, and colleagues (2024) have argued for the greater inclusion of children and youth in research on these topics. As I return to in the analysis, parents are very aware of these aspects but also challenge whether privacy might actually hinder awareness.

Political influencers: Advocacy and disability on social media

While parent influencers, as described above, produce content related to their everyday lives, they also sometimes engage in advocacy and political debates. It goes beyond the scope of this article to account in detail for the field of political influencing in general, but as Riedl and colleagues (2023) have discussed, political influencers can be seen as another sub-type of influencers, who instead of aiming for commercial gains, build on credibility and authenticity while engaging their audience to promote political opinions and social causes. Political influencers as a concept covers a wide range of practices, and they can play constructive roles in society by increasing political interest, but they may also foster cynicism and fragmentation (Riedl et al., 2023). In the case of the study presented in this article, parents engage in political and social debates and perform advocacy related to aspects of disability rights and representation (Hill, 2023; Södergren & Vallström, 2022), both at a general level and at a rather mundane and concrete level through processes of building networks, inspiration, and support (Kjær, 2022; Neag et al., 2024).

Social media have become a vital space for advocacy, offering individuals with disabilities a platform to share their experiences, challenge stereotypes, and drive social change (Ellis & Goggin, 2015; Johansen, 2024; Trevisan & Farinosi, 2024). While social media create more accessible opportunities for participation, they also present barriers, such as bias and exploitation (Kent, 2019). Kent described the relationship between media and disability as "complicated", noting the dual role of social media in both empowering and marginalising people with disabilities. Hill (2023) explored these complexities by analysing the hashtag #DisabledAndCute, revealing how online discourses can challenge ableist ideas while also reinforcing them. Similarly, Södergren and Vallström (2023) examined influencer marketing's role in disability advocacy, emphasising the need to move beyond stereotypes like "victims" or "superhumans". They advocated for recognising the nuanced and multifaceted identities of individuals with disabilities, rather than reducing them to fixed categories.

As presented above, social media might be empowering, but they also present barriers like bias, emphasising the need for nuanced representations beyond stereotypes. For the purpose of this article, I focus on how the parents in the study engage in political debates, and how they are making use of their online presence to both encourage each other and to advocate for the rights and well-being of their children and for people with disabilities in general.

Methodology

Drawing from an interview study involving Danish parents who openly discuss on social media platforms the challenges they face regarding their children, this article highlights various strategies employed by these parents. The aim of the interviews was to uncover how these parents curate their content, portray their child's diagnosis, disability, and treatment, and perceive their online presence. Additionally, they explored how social media facilitate connections among par-

ents facing similar challenges, while also serving as a platform to raise awareness about the unique circumstances of children living with special needs and engage in influencing through advocacy. Ethical considerations regarding the exposure of their children on social media and the delicate balance between sharing everyday experiences and specific challenges were also central themes of the interviews

In this article I analyse interview data based on five thematic foci: affordances of Instagram, content curation and portrayal, network and support, comparison and competition, and influencing through advocacy, where the latter is presented as an outcome building upon the previous four themes.

Research design

For this study, I have interviewed six mothers of children with physical and cognitive disabilities. Each of them uses social media to communicate about their child(ren) and to connect with others who are in similar situations. To find relevant informants, I used a professional (meaning not my private) Instagram profile (@stinelivforsker) to establish contact with the informants – a profile which I also use to (irregularly) post about my work. The account is open and, over the years, I have used it for non-systematic research among social media accounts relevant for my work. Before contacting users, I familiarised myself with the community, loosely defined as (primarily) Danish accounts in which parents of children with disabilities and/or young people with disabilities share their lives. There is a strong majority of women among these profiles, which also mirrors the fact that two out of three parents who are hometraining their children – as these women all are – are women. I then began using the Instagram chat function to contact users I found relevant. Relevance, in this case, was determined as users with young children who were posting regularly about their child with a specific focus on disability, diagnoses, or both, and who deployed strategies that can be understood as influencing through advocacy. I used a "semi-snowballing" technique in the ongoing recruiting process, meaning that I took advice from the people I interviewed about who to contact next. As such, I intended to meet my informants on common ground where they were able to get to know me a little before saying yes to an interview. I also decided to only familiarise myself with the content of their Instagram profiles at a general level before conducting the interviews, since I was primarily interested in their own reflections and opinions on their media practices and the community they belong to, and the way this relates to their specific life circumstances.

The interviews were conducted either face to face in the informants' homes or online via Zoom, depending on the physical distance and informants' preferences. The interviews lasted between 50 and 75 minutes and were conducted using a semi-structured interview guide (Brinkmann & Kvale, 2015; Tracy, 2020). However, in most cases, the interviews turned into narrative interviews (Brinkmann & Kvale, 2015) where the informants told me the story of their family and particularly of their child with disabilities.

Some of the informants opt to associate their profiles directly with their child, incorporating names or diagnoses into their profile titles, such as "Mum of X"

or "Life with Y". Their sharing habits, follower counts, and engagement with sponsored or commercial content vary considerably, from about 600–800 to 4,000–5,000 followers. As I return to in the analysis, they all reported that they went from having just a few hundred followers, primarily friends and relatives, to having a wider audience. Typically, the children involved in the study are between the ages of 2 and 6 and contend with a spectrum of diagnoses, typically caused by either rare genetic syndromes or brain damage due to oxygen deficiency at birth, each presenting distinct physical and mental hurdles, including cerebral palsy, epilepsy, and mental disabilities. Some of the children were diagnosed at birth or shortly after, while for others this happened later when it became evident that they were not developing according to their age. Also, there is a large variety in the severeness of the diagnoses and therefore also the expected long-term development for each child. To protect the anonymity of my informants and their families, I have chosen to not provide more specific information about each of them. Although their profiles to some degree vary in content, aesthetics, and number of followers, and although their children are living with different diagnoses, the interviews revealed that they have a lot in common, and I focus mostly on these commonalities in the analysis. All names (of parents, children, and siblings) have been replaced with pseudonyms in this article.

The six mothers interviewed all take care of their children at home and are compensated for their loss of earnings by the municipality. According to Danish legislation, parents of children with chronic and severe diagnoses or disabilities are entitled to a monthly fee similar to their previous earnings. Further, they have the right to be compensated for equipment and tools (wheelchairs, cars, etc.) and for access to support and coaching regarding their child's development, care, and home training. As such, they benefit from living in a welfare society, and, unlike parent influencers described in studies such as Jorge and colleagues' (2022), they do not necessarily have to supplement their earnings through commercial content on their social media profiles.

The interviews were conducted in Danish and were audio recorded and transcribed for further thematic analysis. The analysis was done using Danish transcripts, and only quotes used in this article have been translated into English. Each of the interviews was coded with a focus on understanding parents' reflections on their practices and the paradoxes they represent, balancing children's privacy with their own urge to seek support, build community, and advocate for their children. Before diving into the analysis, I explain how and why the interviewed parents began using Instagram regularly, as well as their process of building their profiles and follower bases.

Findings

As mentioned above, there are differences among the interviewed parents regarding when and how they became aware that their child is seriously ill, has a disability, or is otherwise expected to develop differently from most children. For some, this realisation occured at birth or shortly thereafter, while for oth-

ers, it happened later in the child's life. Some have received a specific diagnosis, while others have (yet) to receive a name to put to, for example, a genetic defect. Similarly, the children have different prognoses concerning quality of life, opportunities, and lifespan. Nevertheless, it is common to all six interviewed parents that, coinciding with the child's diagnosis or assessment, they decided to use social media more actively and specifically concerning their child. Several mentioned that, in the beginning, it was primarily a practical measure to keep family and friends updated on hospital visits and the child's development, as it is time-consuming to inform them individually. One mother, who began posting regularly on Instagram when she started home-training her son, described it like this:

> So, I created that Instagram profile because we had a lot of friends, acquaintances, and family who wanted to keep up with us. Every time we had visitors, they would ask, "What can he do now? What can he do now?" And it was the same questions over and over again. And it was, of course, well-intentioned; people were asking because they were interested. And that was really nice. But I was giving the same answers every time. So, I decided to create this profile because then I could say, "Go in and check there, go in and check there to see what we've done today", because I need to talk about something else. I am in this 24 hours a day, and when I finally have visitors, I actually need us to sit and talk about something – anything – that's happening in the world. (Heidi)

For all parents in this study, the motivation for using social media in relation to their child has a double focus. On the one hand, as mentioned above, they intend to inform their personal and extended network about their experiences, and on the other, and very importantly, they use social media to search for guidance, inspiration, networking, and support – and increasingly, over time, they also began to see themselves as someone who could inspire and help others. The decision to approach a broader audience by making their Instagram profile open and by posting regularly was not necessarily deliberate, driven rather by either a wish – as described above in the quote – to make communication and information about the child's condition more convenient or an increasing engagement in the community of parents in similar situations, as I discuss below.

As the number of followers on social media platforms grows, it prompts a shift in how the parents perceive and manage their online presence. Helle reflected on this change, noting that with an increasing follower count comes a heightened awareness of the audience's composition and scrutiny. She observed, "I can feel that it has changed after more people joined. Because I'm not quite sure who is looking at me. Who is paying closer attention". The uncertainty about who is observing and the nature of their engagement leads some of the parents to a more deliberate approach to content sharing. I return to broader reflections on sharing practices in further detail below and nuance how a growing follower count for some parents can perhaps also lead to a feeling of anonymity, or at least a more open space in which discussions can be taken more freely. Cecilie remarked:

> It's strange because I don't think I share very much on Facebook, and I, um, I don't know, it just seems, I find it more intimidating to share with the 300 people I have on Facebook than with the almost 1,000 people who follow me on Instagram, and I simply can't explain why, no.

This observation reveals the paradoxical nature of social media sharing, where users' sense of intimacy might not be dependant on the size of their audience, but rather on their experience of being part of a community. These quotes collectively illustrate the nuanced dynamics of social media for the parents, reflecting both the limitations of online communication and the strategic considerations behind sharing personal experiences.

The parents also mentioned their desire to help others who recently had a child diagnosed with disabilities. They vividly recalled the feelings of being overwhelmed, insecure, and desperate for relevant information and support. For many, their initial attempts to find guidance were met with frustration, as the available resources often felt impersonal, outdated, or overly clinical.

One mother recounted how she initially scoured the Internet for insights into her child's challenges but eventually found a sense of belonging and hope on social media, thanks to the use of hashtags:

> If you google brain injury and cerebral palsy, which is the diagnosis he has been given, it doesn't inspire much hope. But then I found out that, through social media, you could search using different hashtags: #braininjury, #hometraining, #cerebralpalsy, and all these different hashtags that mothers use who write about their children with brain injuries or other disabilities. And there was a kind of network, something you could see yourself in, and something where you could find hope. (Catrine)

Through this process, these mothers not only found a community but also began to actively contribute to it. By sharing their personal experiences, challenges, and practical strategies, they offer a lifeline to others who are just beginning their journeys. Their content – ranging from heartfelt reflections to detailed advice about therapies, equipment, or everyday coping mechanisms – sheds light on life circumstances unknown to most people. This holds the double purpose of creating resonance within the community and creating awareness and visibility for a wider audience who are not familiar with the everyday struggles of these families.

Affordances of Instagram

Instagram is the preferred platform for the parents in this study. Some of them also participate in designated groups on Facebook regarding, for instance, specific diagnoses, but they all expressed how Instagram is where they feel part of a community of peers who have similar challenges. The parents specified, however, that Instagram's format often complicates the ability to convey the full depth of personal experiences. As Catrine highlighted, there can be a struggle to maintain authenticity and accurately represent one's life amidst the constraints of the platform:

> It's such a difficult medium, in many ways. Instagram. Because you have a certain number of characters, and maybe a caption. But all those nuances and thoughts and reflections behind it – they are really difficult to convey. Because it can, you know, be interpreted in many different ways. And I am quite sure that sometimes there are people who look at my profile and think, "oh, they've had it easy".

The ephemeral nature of Instagram stories, which disappear within 24 hours, allows for differentiated types of content. Thea noted, "because, well, the story, it's the one that's gone within 24 hours. So it's very much a snapshot of the moment. Um, whereas what I post, those are more, well, thought-through things ". This distinction between temporary and permanent content underscores the challenge of balancing immediate snapshots with more considered reflections. In the following, I look more closely into how and why the parents decide to share in the way they do, and how these curating practices enable them to build an authentic and relatable image of themselves and their children to allow their followers to better understand their perspectives. As presented earlier, authenticity is described as the key for influencers to persuade their followers to make specific purchases, and so on. In this case, the overall goal can be said to use the authentic and relatable content to educate followers and build empathy in them.

Content curation and portrayal

Parents employ different strategies for sharing their children's lives on social media, often influenced by their child's diagnosis, specific challenges, and everyday circumstances. A key consideration is whether the child might grow up and reflect on what was publicly shared about them when they were younger. For example, Helle carefully decides what to photograph in the moment, ensuring that the images do not capture her child or herself in distress:

> I would definitely find it difficult if I were that child, to look back in a few years and have my friends see and hear stories about me being sad or… I feel it becomes too private, in a way, to share it.

This concern reflects a broader trend where parents are increasingly mindful of their children's digital footprints and the potential future impact of shared content. Helle emphasised how her approach differs from others who share extensively about their children, suggesting a nuanced understanding of privacy and consent.

Heidi echoed this concern about the implications of sharing personal moments: "I'm thinking a bit about what exactly I want with this, like, why exactly am I doing it? But I think it all comes down to destigmatising certain things". Heidi's statement highlights a balancing act between openness and privacy. While she is motivated by a desire to reduce stigma, she is also conscious of the long-term impact of her sharing. Similarly, Naja reflected on how her frustrating circumstances affect her sharing practices:

> Well, I almost always think about what I write. Sometimes I might write something, and then five minutes later, I think, "That wasn't very smart". Then I just delete it again. What could it be? Well, if it's personal things, you know, like... "Oh, I just can't handle this anymore", or "Now she's going to an institution", or that kind of "I've had enough", right? And even though I think people understand how I feel, it might send the wrong signal to others that I can't handle the situation I'm in. So, in those situations, I might end up deleting it again.

Naja's experience reveals the emotional complexity involved in sharenting. She navigated a frustrating situation that significantly impacted her social media practices. She frequently reconsiders and deletes posts that express her feelings of being overwhelmed; even though she believes others might empathise with her emotions, she worries these posts could give the impression she cannot manage her responsibilities. The challenging circumstances she faces leads her to continually evaluate what she shares, revealing the tension between expressing her genuine struggles and maintaining a controlled public image.

Networking and support

Across all six interviews, the informants highlighted the significant role Instagram plays in alleviating feelings of loneliness and isolation following the diagnosis of their child's condition. Parents expressed a common experience of feeling deeply alone during the initial stages of their child's life or upon receiving a diagnosis. They lacked access to peers who could relate to their experiences and provide both emotional and practical support.

Heidi described how Instagram became a critical tool in helping her process her grief and find acceptance:

> Well, Instagram helped me to actually… to process a sorrow, and to accept. To see, well okay, there are other people in the world who also have a child with disabilities. I felt all alone in the beginning. I felt that it was very taboo. There is so much prejudice.

Thea mentioned how Instagram facilitated connections beyond the specific medical conditions of children:

> It is also, well, a network across different diagnoses. Yes. Because I only know of one child, diagnosis-wise, that matches with [my child]. But still, it's the same concerns that you have, no matter how your child is ill. Whether it's genetic, brain damage, or whatever it is.

The above quote emphasises that while their children may have different medical conditions, parents still face common challenges and concerns. Instagram allows them to exchange information and experiences that are broadly applicable, such as dealing with municipal support systems, securing assistive devices, or managing daily life routines.

Furthermore, the sharing of personal stories and day-to-day experiences on Instagram fosters a form of community-building that combines emotional sup-

port with practical advice. Heidi and Thea's reflections show that these online interactions are not limited to sharing feelings of loneliness or frustration but also extend to tangible, actionable advice. For instance, Thea mentioned the value of exchanging practical solutions: "There is so much you can share. And also, just exchanging experiences with, well, municipalities. And assistive devices. And daily life. And asking, how do you handle this? How do you solve this problem?" This sharing of practical knowledge allows parents to learn from each other's experiences, thereby alleviating some of the stress and confusion they may feel when navigating complex support systems or dealing with unexpected challenges. And, as presented below, these networks not only alleviate feelings of isolation but also serve as springboards for collaborative efforts and collective action. Openly discussing controversial or complex issues is a way for them to challenge societal norms, shift perceptions, and encourage more inclusive policies and practices.

Comparison and competition

As outlined above, parents described the Instagram community as a valuable source of support and solidarity. However, they also focused on how comparison subtly creeps in, impacting the way parents perceive their own situations and their children's progress. This duality is highlighted in Catrine's reflection on her experience within such communities:

> There are certainly some profiles that want to outdo each other. The same themes are often brought up, and they might inspire each other in that way. Like, "Now my daughter can climb stairs, or what do you call it?" Then someone else might think, "Well, I have to show that my son can do that too". […] But people are also good at referring to each other: "Oh, has your son been diagnosed with that? You should definitely write to her". As I said earlier, it's a really nice community where people genuinely support and help each other a lot.

Catrine's observations highlight a significant downside to the otherwise supportive nature of these online spaces: the underlying competition that can emerge among parents. The comparison often stems from a natural desire to celebrate their children's milestones and achievements. However, this celebration can quickly turn into an unspoken contest of sorts, where parents feel pressured to showcase their child's progress or capabilities. For example, when one parent posts about their child climbing stairs, others might feel compelled to respond by highlighting their own child's accomplishments, such as not needing to use their hands.

This sense of competition is often subtle and not overtly acknowledged. As Catrine noted in the quotation above, the comparisons are not "very explicit when people write to each other", suggesting that the competition is more of an undercurrent than an overt rivalry. Nonetheless, it can create feelings of inadequacy or stress among parents who feel their child may not be progressing as quickly or impressively as others. However, this competitive element is

counterbalanced by a genuine culture of support and resource sharing. Parents frequently refer one another to helpful contacts or resources who have been facing similar challenges. This demonstrates a strong sense of camaraderie and a willingness to help others navigate the specific everyday struggles they are all familiar with, reflecting the community's overall positive intentions.

Influencing through advocacy

As we have seen so far, Instagram's affordances allow the parents to build audiences and to post either snapshots in the moment or more thoroughly curated content, reflecting their everyday struggles as well as their considerations of how to portray their child online. Further, they are building strong networks of peers, which are highly valued but also sometimes competitative. Their advocacy practices stem from this network, rather than from individual aspirations of pursuing political goals. In the following, I argue that the parents – on at least three levels – perform influencing practices (as described in Blum-Ross & Livingstone, 2017; Jorge etal., 2022; Ruiz-Gomez et al., 2024) and use their social media presence to address and change societal prejudice against people with disabilities or the level of social service they experience. The first level addresses the general policy regarding people with disabilities and the political discourse in this area. A specific example of this was the social media campaign #undskyldvierher [#sorrywearehere], which was a hashtag that caught a lot of attention in 2023 after a comment from the Danish minister of finance, Nicolai Wammen, indicated that municipal budgets were challenged by rising costs of the so-called specialised social service area, meaning services for people with special needs. This sparked a campaign in which people with special needs – or their parents – used social media to ironically apologise for their existence. Cecilie described her engagement in this campaign:

> I actually think it went quite quickly with that #undskyldvierher campaign, like it just caught fire. There had been something simmering there. […] The problem is that we are parents and relatives who are up to here with it. I mean, we're just barely able to catch our breath now and then. So, the feeling of drowning, and then also having to say, "I am actually drowning", can make it really hard to find the resources to do it. So, I think that when something like that spreads, when it starts, it's something we can join because it's not that demanding. It doesn't require me to make a poster, or find a babysitter, or stand at Christiansborg [the Danish Parliament] all day. So, it's a call to action and a demonstration that we can participate in without exhausting our very limited resources.

The second way in which the parents in this study aim to influence public opinions is closely related to the political discourse, but also addresses a more general intention to make people with disabilities visible, and thus to overcome the historical invisibility of people who do not fit societal norms. Heidi put it like this: "It's exactly that – I don't want to hide him away. No, because that's what was done 50 years ago. Back then, they were just hidden away". Yet, visibility

is also a matter of being seen as a concrete human being in a specific context. As Cecilie described, she intends to let the world know that her daughter – although her life mostly plays out in the home and not in the social contexts, where other children have access – is still worthy of attention:

> But I think that it has something to do with giving them a life and a voice, like everyone else. To make them visible. Because her brother is visible in kindergarten and her sister is visible at daycare, but [name of child], she is just here at home. So, I think it is a matter of taking these opportunities [of social media] and using them.

A third way in which the parents in this study use social media for advocacy purposes relates to their concrete collaboration and challenges with the municipality, especially when it comes to concrete aid and tools, which they sometimes must argue for intensively. Some of them explain how they try to balance speaking up for their rights, while not being too provocative and unintentionally damaging their own case. Naja explained how she reconsidered her approach:

> Sometimes it's the municipality that doesn't work. The case processing times, all the rejections, all those kinds of things. […] Well, it sounds a bit crazy, right? But in the beginning, I didn't care about what I posted concerning the municipality. And I almost felt like strangling them all or something like that. But I've realised that they are also reading along. So, in a way, I feel like things work a little better if you're just not as active in your aggression towards them.

For other parents, this way of using social media to debate the service level in the municipality is also something that can be considered tiresome or too much:

> Complaints about the municipality or all sorts of other things. And I think that's a narrative that's circulating. I mean, to such an extent that I often get really tired of reading people's posts. Because there is so much of, well… what I'll call negativity. It's real enough, of course. Complaining about mistreatment by the municipality, complaining about or talking about system-related stress, and all these things that are entirely real and which I respect. (Catrine)

The examples above demonstrate that parents of children with disabilities engage in diverse practices of influencing through advocacy. Through campaigns like #undskyldvierher, they tap into collective frustration and transform it into a low-resource, highly accessible form of advocacy, effectively amplifying their voices without overextending their already limited capacities. At the same time, their advocacy extends beyond direct activism. By sharing personal stories, they challenge historical invisibility and assert the humanity and individuality of their children. Finally, the parents' interactions with municipal systems highlight the complexities of advocacy in bureaucratic contexts. They must carefully balance their frustration and demands to maintain a constructive dialogue, even as they struggle with systemic inefficiencies.

Discussion

Social media, particularly Instagram, serve as vital platforms for parents of children with disabilities, enabling them to alleviate feelings of isolation and foster connections with others who share similar challenges. Their use of social media bridges the roles of parent influencers and political influencers, blending personal advocacy with broader social and political debates. Consistent with the work of Södergren and Vallström (2023) and Hill (2023), these platforms offer spaces where marginalised groups can build solidarity and challenge societal stereotypes, albeit within contexts that remain sites of negotiation and contestation.

The sense of community on social media often provides emotional support and practical advice, aligning with research that underscores the importance of authenticity in influencer practices (Arriagada & Bishop, 2021; Hendry et al., 2021). However, this dynamic is not without its challenges. Parents occasionally reported feelings of competition when sharing milestones or achievements, reflecting the dual nature of social media as both a source of empowerment and a potential source of stress (Kent, 2019). Despite these tensions, the overarching culture remains collaborative, with parents frequently sharing resources, contacts, and advice, demonstrating the communal intent behind these online interactions.

By sharing their children's stories and participating in campaigns like #undskyldvierher, the parents challenge societal biases and advocate for disability rights, mirroring the role of political influencers who build credibility, authenticity, and relatability to drive social change (Riedl et al., 2023). This advocacy aligns with broader observations that social media serve as a critical tool for shaping perceptions of disability and promoting inclusion (Ellis & Goggin, 2015 Johansen, 2024; Trevisan & Farinosi, 2024).

Parents aim to balance authenticity, advocacy, and ethical considerations in their sharenting practices (Leaver, 2020; Blum-Ross & Livingstone, 2017). Their online presence raises essential questions about privacy, representation, and the agency of children with disabilities (Goggin & Ellis, 2020). While concerns about commodification and the long-term implications of sharenting are valid, this study highlights the nuanced realities of parents who use social media as a platform for support, networking, and advocacy. Parents in this study use Instagram not only as a tool for navigating the complexities of parenting children with disabilities but also as a means to drive social change. This dual role, blending personal storytelling with broader advocacy, underscores the multifaceted nature of influencer culture and highlights the potential of social media to effect meaningful societal change.

Conclusion

The findings highlight the complex use of social media by parents of children with disabilities, revealing both opportunities and challenges. Initially, social media platforms like Instagram are used to update family and friends; however, over time, they evolve into vital tools for support, community building, and

advocacy. Parents use these platforms to connect with others facing similar challenges, sharing experiences and gaining emotional and practical support.

A key challenge is balancing openness and privacy in their online presence. As parents engage in sharenting – sharing their children's experiences while considering the long-term impacts and potential privacy issues – they are aligning with the concept of privacy stewardship as suggested by Leaver (2020). The interviews show how this is a complex process in which they seek to consider the privacy of not only themselves and their child, but also their partner, other children, and professionals like doctors or social workers – while also insisting on visibility as an important part of how they intend to influence public discourses about disability.

Over time, their consistent presence and relatable stories earn them a following. Some take on the role of guides, offering step-by-step advice on navigating complex healthcare systems, applying for support services, or managing the emotional toll of parenting a child with disabilities. Others focus on fostering a sense of hope, showing through their own journeys that progress, joy, and normalcy are possible. By engaging authentically and empathetically, these mothers gain influence, not in a commercial sense but as relatable peers and advocates. Their influence is rooted in shared experience and trust, making them important sources of encouragement and inspiration to other parents who might otherwise remain isolated. To some extent, this is a general factor for many parents who are using social media to seek or give advice about parenthood, but the specific life circumstances, which they share, are what separates this group of parents. Uncertainty about their children's diagnosis, treatment, and development, combined with an everyday struggle to secure that they get the best possible care, distinguishes them from "normal" worries of parental life. And they are even more reliant on peers who understand these circumstances.

This grassroots influence often extends beyond individual connections. By advocating publicly for greater understanding and inclusion, they help to challenge stereotypes and raise awareness of the realities faced by families of children with disabilities. In doing so, these mothers not only empower other parents but also contribute to broader societal conversations about disability rights and inclusion. In this way, they add nuances to the definition of an influencer. Their role is not about commercial gain but about fostering community and driving change – both within their immediate networks and in the wider public sphere.

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