Social Inclusion
Open Access Journal | ISSN: 2183-2803

Volume 7, Issue 1 (2019)

People with Disabilities: The Overlooked Consumers

Editors

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COGITATIO

Social Inclusion, 2019, Volume 7, Issue 1
People with Disabilities: The Overlooked Consumers

Published by Cogitatio Press
Rua Fialho de Almeida 14, 2º Esq.,
1070-129 Lisbon
Portugal

Academic Editors
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Available online at: www.cogitatiopress.com/socialinclusion

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2019, Volume 7, Issue 1, Pages 111–113
DOI: 10.17645/si.v7i1.1952

Editorial

People with Disabilities: The Overlooked Consumers

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Submitted: 31 December 2018 | Published: 31 January 2019

Abstract

This thematic issue aims at developing and disseminating knowledge about how consumption can promote and inhibit social participation and social inclusion through increased access to and use of marketplaces, goods and services. This editorial briefly presents the topic and summarises the different articles published in the issue.

Keywords

accessibility; consumption; disability; equal rights

Issue

This editorial is part of the issue "People with Disabilities: The Overlooked Consumers", edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

1. Introduction

We are all consumers with varying levels of abilities who acquire, use and dispose of goods and services in everyday life. Access to vital consumer goods and services is linked to the human right of being a full member of society and living an independent life. However, consumers with disabilities face greater barriers due to reduced access to products and services, despite the legislation that has been implemented to enhance the situation (Kaufman-Scarborough, 2015). It is estimated that between 15.6% and 19.4% of the world's adult population live with some kind of disability (WHO, 2011). In fact, most of us will at some point in our lives experience short- or long-term disability due to illness, accident or age (WHO, 2011).

This thematic issue aims at developing and disseminating knowledge about how consumption can promote and inhibit social participation and social inclusion through increased access to and use of marketplaces, goods and services. The authors of this thematic issue address the challenges that consumers with disabilities face in everyday life and examine whether some markets, products or services are more challenging to access than others. Furthermore, some of the included articles analyse which interventions have been implemented at different levels to improve the situation of consumers with disabilities; others explore how well the interventions function while pointing out potential areas for improvement. The articles encompass the experiences of consumers with varying levels and types of disabilities, including mental, cognitive, physical, visual or hearing ones. Based on exploratory qualitative studies, the authors discuss the experiences of this often overlooked consumer group and suggest directions for further research.

2. Short Presentation of the Articles

In the first article, Daniels (2019) criticises the way mothers with disabilities are treated by the society, including inadequate healthcare services and non-accessible goods and services at consumer markets. Based on autoethnographic material and literature on the topic, she gives examples of the discrimination encountered in their everyday lives. She urges the need for recognition and adequate support to ensure that disabled women can get smoother transitions into motherhood.

Laitala and Klepp (2019) describe the daily difficulties people with ostomy, or chronic skin disease, face as clothing consumers. They explore the various challenges, as well as the related coping strategies, people use for concealing the condition and the connected bodily secretions, but they also highlight the potential for social exclusion when these strategies fail.

Borch and Strandbakken (2019) show that the evaluation of new ideas for technologies that improve energy efficiency vary somewhat between people with and without mild forms of disabilities. People with mild forms of disabilities show more engagement, likely due to their experiences with increased needs and economic constraints. Their study indicates that it is likely beneficial to include people with disabilities in the innovation processes in order to make the new technologies accessible to larger portion of the population.

Samuels (2019) studies how inclusive music making with accessible technologies contributes to the lives of participants with different abilities and how the workshops contribute to improving their confidence, creativity and social skills, thus having a broader impact on social inclusion. Mainstream consumer music technology devices can be made more accessible with adaptions, but at the same time, the main challenge in the workshops is the use of these technical tools that demand focus from the facilitator away from the participants.

Kaufman-Scarborough (2019) shows that many restaurants and venues provide either incomplete or incorrect accessibility information, which does not comply with civil rights laws in the USA. The information provisions for different types of disabilities vary, and restaurants usually cover information only for consumers with physical disabilities; the larger venues are better at also informing consumers with vision, hearing and sensory disabilities. Kaufman-Scarborough calls for a universally regulated communication design for accessibility information.

Closing this thematic issue is a commentary by Warnicke (2019) who shows that deaf citizens in Norway do not have equal access to make emergency calls as other citizens; the situation in Sweden is better, however, but limitations still exist. Warnicke recommends that social services must meet all accessibility requirements to protect the rights of every citizen.

3. Conclusions

Overall, the authors show that despite improved accessibility and non-discrimination legislation and existing inclusive design principles, many products, services or marketplaces remain difficulty to access for this overlooked consumer group (Noonan, 1997/2007). There is a need not only to enforce the universal inclusion design principles but also to raise awareness in society in order to fight unintended discrimination that often occurs at the unconscious level. The authors suggest various strategies, such as the inclusion of consumers with disabilities in innovation processes, to ensure that a range of adaptive solutions become easily accessible to meet needs of a diverse range of people. These articles also highlight how including consumers with disabilities in the study adds another perspective to consumption research that enriches our understanding of the studied field as such.

Acknowledgements

This issue has been made possible by the strategic research priority area "Inclusive Consumption", focusing on vulnerable consumers, at the Consumption Research Norway—SIFO, Oslo Metropolitan University.

Conflict of Interests

The authors declare no conflict of interest.

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Social Inclusion (ISSN: 2183–2803)
2019, Volume 7, Issue 1, Pages 114–123
DOI: 10.17645/si.v7i1.1551

Article

Disabled Mothering? Outlawed, Overlooked and Severely Prohibited: Interrogating Ableism in Motherhood

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Submitted: 23 April 2018 | Accepted: 15 October 2018 | Published: 31 January 2019

Abstract

The ideology of motherhood precludes disabled people in various ways: sometimes outlawing it completely, in the case of enforced or coerced sterilisation; sometimes condemning it through the sanctioned removal of children and/or adoption; and at other times complicating it severely through lack of access to accessible goods and services that all mothers require to function in their day-to-day lives—such as pushchairs/prams, baby-changing equipment and baby-wearing apparatus. Ableism, "compulsory able-bodiedness" (Campbell, 2009; McRuer, 2013), will be used as an interrogative tool to aid in the 'outing' of the 'able': to tease out the values and principles undergirding this exclusionary perception of motherhood. As such I will be drawing on autoethnographic material, in conjunction with a Studies in Ableism (SiA; Campbell, 2009) approach to analyse the bypassing of disabled mothers and to suggest tentative ways forward. In the UK 1.7 million parents identify as disabled (Morris & Wates, 2006) and perhaps many more would do so if there were no fear of censure (see, especially, Booth & Booth, 2005; Llewellyn, McConell, & Ferronato, 2003; Sheerin, 2001; Swain, French, & Cameron, 2003) and their requirements need to be recognised, heard and provided for in the consumer market. The following article will articulate how disabled mothers are barred from the sacred hallow of motherhood, and delineate the need for the media, governmental organisations and marketing corporations to address their culpability in this blatant discrimination.

Keywords

ableism; disability; ideology; motherhood; normativity

Issue

This article is part of the issue "People with Disabilities: The Overlooked Consumers", edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

> There exists an astounding disparity in knowledge about the reproductive health of disabled versus non-disabled women; virtually nothing is known about the number of disabled women of childbearing age, or their rates of fertility, pregnancy birth and abortions....This state of affairs should come as no surprise: "If research pursuits reflect social values, it makes sense that a society that has long ignored the gender role of women with disabilities has invested little effort in understanding their potential for love, partnership and motherhood" (Gill, 1996, p. 189). (Prilleltensky, 2003, p. 22)

1. Introduction

Although the actual numbers of disabled mothers in the UK is difficult to establish, it is true to say that we are a growing number, with a spending power of over £200 billion per year (Scope, 2018). There are many factors which disable a person according to normative criteria—energy fluctuations, physical embodiment, narrow societal definitions of cognitive capacity, the limited ability of society to communicate using sign language or Braille—and some, although not all, can be partially relieved through greater social access and inclusion. The social imaginary, however, that disability in and of itself must surely prevent a disabled woman from exercising her human right to become a mother often operates at the unconscious level of society's collective genealogy. It manifests itself in the lack of provision of adequate goods and services to ensure smooth transitions into motherhood for many disabled women. This points to a residual undercurrent of ableism in the arena of reproductive liberty. The association with eugenics (see Frederick, 2014) has prevented this view from being explicitly recognised, but the regularity of routine screening practices for pregnant women has ensured that the reverence of 'perfected' ableness is alive and well. The following article hence, will probe why it is that disabled mothers may be discouraged from entering motherhood; how this takes place; and with what effect. I will draw on a number of resources to do this—my autoethnographic data as a disabled first-time mother; analysis gleaned from a review of theoretical literature to reflect the on the implications of mothering ideology as it relates to disability; and a strong orientation to the insights gained from studies in ableism (SiA). There have been many studies carried out, particularly in an Australian context, exploring the explicit outlawing and prohibiting of disabled mothering (for notable examples see Booth & Booth, 2005; Frohmader & Ortoleva, 2012; Steele, 2016; Tobin & Luke, 2013; Zampas & Lamačková, 2011). What I aim to do with this piece is to bring to the fore the implicit, the nuances—the microaggressions and internalised ableism, or what Campbell (2018, p. 25) terms as "ontoviolence"—the harm inflicted onto one's very *being*—of the non-recognition of disabled mothers, reflected in the absence of adequate supports and provision (Pendo, 2008). My investigation here is two pronged: firstly, the objective is to 'out' the 'able', to articulate the values embedded within the ideology of motherhood and to what extent these are ableist; and secondly to investigate the more subtle pressures many disabled women experience to refrain from reproducing. The contribution of this research to the field, therefore, is to analyse the combination of motherhood and disability in the light of ableism theory.

There are differences in the use of the term 'ableism' across different contexts. My usage of the term follows Fiona Kumari Campbell (2009) and Dan Goodley (2014). Campbell (2014, p. 84) identifies:

> Ableism as a mentality and practice is inherently narcissist. As a practice ableism demands an unbridled form of individualism, which is preoccupied with self-improvement and corporeal enhancement, and struggles with the reality of illness, disability and misfortune.

Gregor Wolbring (2008) describes ableism as a favouring of abilities, and the eternal othering placed upon those who apparently do not possess these socially prescribed 'essential' attributes. Ableist normativity treats disability as a state of exception, meaning that disabled people have to be treated as Other, as separate, and as deviant. Disabled people, thus, are by and large dealt with as an afterthought in society, and their needs are not met with alarming regularity. SiA reaches into the very foundations of disablism, which here is defined as discrimination against people due to actual or presumed disability (Goodley, 2014), to interrogate the roots of this oppression. As Campbell (2009, p. 5, as cited in Campbell, 2017, p. 8) states:

> Ableism is deeply seeded at the level of epistemological systems of life, personhood and liveability. Ableism is not just a matter of ignorance or negative attitudes towards disabled people; it is a trajectory of perfection, a deep way of thinking about bodies, wholeness and permeability. Bluntly, ableism functions to "inaugurat[e] the norm".

In other words, ableism serves to cast "normative shadows" (Overboe, 2007, p. 27) over human ways of being, an ethereal feeling that "one is constantly being judged according to different [and unstable] criteria of normality". The race for perfection, in this light, is marked as being futile and essentially *un*productive. The project of ableism I aim to develop in this article is to unmask the values undergirding the ideology of motherhood (ableism's production) and to analyse how we as a society reinforce these values (ableism's performance). Following on from Goodley (2014) and Campbell (2009), my aim here is to use the assumption of able-bodied and able-minded motherhood to shed light on the beliefs, principles and standards underpinning the infeasible articulation of the 'ideal mother'. My intention is that by naming and explicating this figure we can come to expose the ableism lurking within it.

2. Methodology

I became disabled at age 19 through a road traffic accident which caused a traumatic brain injury, broken neck and permanent loss of feeling and movement in my right arm. The impact caused a collapsed lung, and the incubation procedure resulted in a paralysed vocal cord. I first became a mother on the 12th of August 2016, and am in the third trimester of my second pregnancy. I recorded my autoethnographical experiences of my first pregnancy and early motherhood in the form of field notes. My experiences of trying to negotiate these normatively oppositional identities, in conjunction with a firm grounding in disability studies and SiA, is used to strengthen my critical positionality and shed light on the discriminating practices of motherhood. A theoretical literature search was used to select, summarise and analyse the breadth of literature available on mothering, mothering ideology, intensive mothering and disabled mothering. The literature was then ordered thematically and by source (for example, autoethnographical material from disabled mothers; studies carried out by non-disabled researchers, etc.). This was then used to focus the specific research questions that, in my opinion, remain unanswered by previous studies. These questions are related to the exclusionary reverence of motherhood and to what extent this precarious approval is ableist:

1. What is it specifically that is valued in motherhood, and in what ways are these values ableist?
2. How do we as a society uphold and reinforce these values?
3. How can the study of ableism be used first to expose then to challenge and break down these stifling structures in order to forge a path for more creative mothering practices?

For the purposes of this article, the resulting analysis rests on an unfaltering bias, influenced by my positionality and as such omits many important perspectives such as the experiences of mothering older children and disabled fatherhood. These could of course be directions for future studies. Whilst I acknowledge that various impairments will have differing needs, I refer in this article to all disabilities regardless of their nature. The article is intended to be a theoretical reflection on the potential psychological and emotional position of disabled mothers in western society pursued with an ableist lens.

3. Ableism's Production: The Configuration of the 'Good Mother'

What can the study of abledment (Campbell, 2018)—the assumption of ablebodiedness—tell us about mothering? The ideology of mothering in its dominant narrative parallels neoliberal configurations of the ideal citizen (De Benedictus, 2012; Goodley, 2014; Fritsch, 2017; Lupton, 2012) and at the same time reinforces and demands conventional depictions of women. Ableism infiltrates this idealised version; it is clearly and strictly articulated and symbolised in both explicit and covert ways. My research into the ideology of motherhood (Daniels, 2018) suggests that the 'approved' mother holds a number of valued characteristics: physical dexterity; fast pace; endless energy; emotional, mental and physical stability; and is self-contained, independent and autonomous. Therefore, in the light of ableist and normalised values, it leaves other ways of recognising ideal mothering to be downgraded—kindness, love, support, tolerance, acceptance, interconnection and cooperation—aspects of mothering that I would argue are to be championed, and do not rely on ableist rankings.

There is a long list of 'shoulds', 'always' and 'musts' in the definition of a good mother that many women in the western world have absorbed from media, government slogans, healthcare paraphernalia and their social networks. As Arendell (2000) identifies, the ideology of intensive mothering has morphed the collective social and personal expectations of mothering from being a 'good enough' mother into being an exceptional one (Green, 2015). It is not considered enough to be acceptable or satisfactory; mothers are pushed to be outstanding. This configuration of mothers is tied specifically to the excesses of ableism, pushing at its borders; to be exceptional, outstanding, and thus inherently *not* normal. The seduction of normativity loses its power here as the pressures of compulsory able-bodiedness spiral out of control.

Disabled women, in the above light, are set up in the social imaginary as an antithesis to the ideal mother and citizen, as an example of what not to be. This disablism rests upon a number of problematic assumptions, namely that disabled women are sure to have risky pregnancies, produce disabled (read: unworthy) babies, be a burden on the state, and be unquestionably incapable parents (Campion, 1995). The disablism inherent in these assumptions has been challenged extensively elsewhere (Blackford, 1988, 1990, 1999; Crow, 2003; Malacrida, 2009; Prilleltensky, 2004; Thomas, 1997). The opening section of this article will consider the treatment of disabled mothers through pregnancy and early motherhood and reflect upon the potential internalising of ableist values resulting from this.

4. The Medicalisation of Pregnancy and Early Motherhood

The assumption of a normatively working, non-disabled maternal body is rampant in the ideology of motherhood, resulting in the infuriating lack of provision for maternal bodies who do not conform to these standardised ideals. Through the side-lining and societal disengagement with disability issues, many experts do not know how to adequately treat pregnant disabled women. This leads some doctors to treat the pregnancy in an "alarmist way" (Campion, 1995, p. 136). The lack of appropriate access to, for example, examination tables and other perinatal facilities (Tarasoff, 2017) for some women enacts a substantial barrier to their care. As Frederick (2017, p. 79) notes, the assumption that disabled women cannot or should not have babies, in conjunction with the project of normalcy, mean that the unique needs of disabled mothers are often rendered invisible. This misrecognition results in the market provision of products, goods and 'expert'-driven advice manuals to be chronically underdeveloped for this population (Pendo, 2008). The prizing of bio-medical normalcy (Frederick, 2017) and the deep-rooted devaluing of disabled existence mean that the opportunity to access suitable products aimed at, for example, enhancing children's development is limited if the mother differs from the norm. Through the lens of ableism we can come to critique this failure.

The ableist gaze that follows many pregnant disabled women is a profound factor in influencing their confidence in performing mothering tasks. The compulsion towards enacting able-bodiedment is still an oppressive concern for me. The notion of internalised ableism was a significant factor during my pregnancy, and left me with a deep feeling of trepidation.

> 3rd February 2016. Motherhood is an enchanting, captivating prospect, suffused as it is with tenderness and warmth, and I was deeply excited about it. I felt the flutter of delight thinking about the tiny life that

> was growing inside me. And yet this was marred by feelings of anxiety: how would I cope with a baby with, effectively, one functioning arm? All the mothers on advertising campaigns or in the media are able-bodied, and they seem to go about this role with a gracious ease. I felt that I needed to be as 'able-bodied' as I could, masking and hiding my disability. I feared that if I asked for help, I would be discovered as an incapable mother before the baby was even born, bringing attention to myself and inviting the scrutinising eyes of social services. So I pretended, I passed, I masked. This turned a potentially positive experience into the start of a downward emotional spiral. In a sense, the only real risk came from the lack of adequate support in my environment, and the anxiety of surveillance—both attributable to living in a 'disablist world'.[1]

Women in the UK and other western countries have been shown that there are certain ways of preparing for childbirth that are "culturally appropriate, morally underpinned and socially acceptable" (Miller, 2005, p. 31). Pregnant women are expected to give their trust, and thus a large amount of their lives (and the life within them), over to medical professionals. Whilst I acknowledge that there are many people working within the medical profession who are sensitive to the needs of disabled people, much more needs to be done to ensure that treatment is delivered appropriately and respectfully. The relinquishment of power to medical professionals has significant concern for disabled women as this is a profession, broadly speaking, which has systematically and uniformly negated their bodies.

> 23rd March 2016. I was desperate to be seen to be avoiding risk, to gulp down and seal off the treacherous reservoir of fear inside me that was threatening to engulf me within its depths. Nevertheless, the medical appointments during my pregnancy were always teamed with pointed looks at my hand, to which I felt—not angry, not a proud disabled woman, but a wave of shame. Every time this happened I could feel my face burning, as if my arm had brought dishonour to my body. This was feeding my anxiety and perception of myself as irresponsible, incapable and inherently 'not normal'.

The desperation with which I wanted to be seen to be avoiding unnecessary risk—as if by my very embodiment I am already a 'risky' subject—is an occurrence noted elsewhere in the literature (for example Crow, 2003; Walsh-Gallagher, Sinclair, & McConkey, 2012). My narrative here shows how powerful and seductive notions of normative motherhood can be. The flush of pleasure that I got from the rare times that I conformed to the restrictive mothering role in my early experiences of motherhood eased my anxiety and tranquilised me. The need to prove myself as a responsible 'normal' mother is often overwhelming and utterly exhausting, which reflects the need to develop a more expansive ideology of motherhood that empowers the needs of a diverse society, one that does not seek to include disabled people within exclusive "and individualised relations of neoliberalism" (Fritsch, 2015b, p. 48) but instead seeks to embrace interdependency and connection. Through the sometimes stealthy, sometimes explicit employment of biopolitics on pregnant women, they are highly encouraged to vet their actions through a process of stringent self-regulation, propelled by a plethora of expert guidance—the governing of the self. But the most ingenious fact of this method of biopolitics is that pregnant women are enlisted in the effort of self-regulation as a way to prove 'responsible' motherhood. So insidious is the ableism around motherhood, and so sneaky is it of infiltrating our collective genealogy that we actually come to aspire to normative forms of mothering—often without realising it.

5. The Ableist Biopolitics of the Pregnant Body

Pregnancy, once considered a natural state, has now come to be characterised in the western world in the language of 'risk' (Cahill, 1999). The pregnant woman, thus, has lost her identity and autonomy as far as the foetus is concerned. The body of the pregnant woman itself is considered dangerously unstable and chaotic, with permeable boundaries, in a cultural milieu where static and bounded states are considered ideal (Lupton, 2012). The woman's previous identity as a woman with needs and wishes of her own is gone, replaced with her being solely a vessel for the unborn child. She no longer exists, other than to be highly monitored as a potential risk. The pregnant woman is portrayed as weak and irresponsibly influenced by her carnal desires, and so she must pay unyielding attention to the advice of the medical and psychological experts. This state of Foucauldian self-regulation is the epitome of biopolitics (Rose, 2006). Maternal responsibility and rationality are here intertwined, emphasising individual responsibility for risk management—thus denying or minimising state obligations. Nikolas Rose (2006) surmises that we are entering an era of 'perfected' human abledness, wherein we are experiencing "a qualitative increase in our capacities to engineer our vitality, our development, our organs and our brains" (Rose, 2006, p. 4). This molecular vision of life opens up serious debates around the kinds of societies we want to create, and who is given value within those societies.

6. Interrogating the Foetus

Many research studies (for example Campion, 1995; Kallianes & Rubenfeld, 1997; Prilleltensky, 2004) have focused on the assumption that children born to a disabled mother will inevitably be disabled themselves or

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[1] Excerpt from a personal diary entry with a final reference to Malacrida (2009).

suffer the effects of the maternal disability, which rests on wider assumptions about disabled people and their place in society. The foetus has come to be aesthetically judged as viable and healthy, or as defective. The advances in prenatal testing have positioned certain foetuses as being '"less worthy of the privileges of citizenship than other foetuses, and as liabilities to society" (Lupton, 2012, p. 336). Prenatal tests, once reserved for 'high-risk' pregnancies, are now carried out on a regular basis (Parens & Asch, 2000; Suter, 2002). The axiomatic decision to offer a termination if the foetus does carry the genetic markers of disability is in itself an ableist assumption. It is ableist in the way that society urges us to think and feel that disability is a state that should, if at all possible, be cured or eradicated; in the way that non-disabled life is prioritised and held above all other ways of being; and in the way that this assumption makes disability and disabled people in many crucial ways invisible.

The presumed need and desire to have prenatal testing points to the hegemonic perception that the life enjoyed by disabled people is inherently not as good, not as (normatively) productive, or not as worthy of life enjoyed by non-disabled people. As Saxton (2000) asserts, it also assumes that raising a disabled child will necessarily be an unwanted burden on mothers. There is little discussion of the potential joy, creativity or insight that disabled children may bring to this world. This suggests a need for pregnant women whose foetuses are found to have the genetic markers of 'abnormality' to be counselled honourably about the possibilities and potentialities of having a disabled child. The whole issue of prenatal testing, it can be argued, underscores and predetermines future attitudes to disability in an intrinsically negative way. It conspires with the medical view of disability: that if there is a way to prevent it, then we as a society have a moral and ethical responsibility to do so. In making the argument against prenatal testing Adrienne Asch (2003) points out a number of misconceptions about life with a disability: firstly, that in subscribing life with an impairment to inherently unfavourable conditions, it fails to take into account the impact that discriminatory attitudes and social practices (which can be changed) have on the disabled child's life. Secondly, that it places "unwarranted emphasis" (Asch, 2003, p. 318) on the breadth of a person's opportunity range, rather than concentrating on the meaningful decisions that can be made within that range; and thirdly, that 'lacking' a "capacity, skill or experience" (Asch, 2003, p. 318) is fundamentally a bad thing. Rather, this 'lack' can and does lead to innovative and productive ways of being. This way of viewing disability—as intrinsically and unequivocally detrimental to one's life and one's opportunities—is constitutive of the narrow-minded, prejudiced medical model of disability, a model that most disabled people and their advocates are exasperated by.

7. Ableism's Performance—Debilitating Stereotypes

Disabled women are deemed as being always dependent on others, therefore they cannot have others depend on them as they would be incapable of providing for their needs (Malacrida, 2009; Shaul, Dowling, & Laden, 1985). This assumption arises from the prosaic and clichéd depictions of disabled women as being asexual, dependent and therefore unequivocally unsuited to the role of motherhood, in its dominant narrative (Fritsch, 2015a, 2017; Malacrida, 2009; Parchomiuk, 2014). This is problematic in a number of ways; firstly, by identifying certain individuals and methods of parenting as ideal, it narrows and restricts other means of motherhood by identifying them as deviant and devalued. It is also dependent on a very limited view of caring, and assumes that all caring is physical in nature. This gives little credence to the acts of love, support, guidance, fostering of social awareness, acceptance, and morality. The restriction characterised by such a precarious definition calls for a nuanced view of the responsibilities of a parent; as Campion (1995, p. 140) states: "It could be that a responsible parent is one who ensures the welfare of her child by orchestrating whatever combination of support is required". She goes on to remind us that:

> The physical needs of a baby are very different to those of a 10 year old. It is important to remember that dealing with nappy changing and feeding is a very short-lived stage of a relationship that might last for fifty years. (Campion, 1995, p. 141)

This assumption, Campion states, is also reliant upon the notion that dependency is a "negative, helpless state" (Campion, 1995, p. 139). Dependency can be seen, rather, as an intrinsic element of all relationships in society and the realisation of this helps to bind us together. In this light, dependency and interdependency is not something we should shy away from but something we want to promote.

8. Breaking the Spell: Exposing Ableism

Studies (Malacrida, 2009; Prilleltensky, 2004; Thomas, 1997) have shown that there is often a positive ontological reframing when a disabled woman transitions into motherhood. The new-found status as a valuable mother, blossoming life into this world, in many instances symbolises a fresh change for women previously categorised as little more than a drain on the system. However, there lurks beneath this view a stranglehold of normalcy when the disabled mother fights against all odds to be, or to be seen to be, the 'perfect (self-contained) mother'. The mother who can do it all herself, with no help from anyone else (Fritsch, 2017). Studies (Prilleltensky, 2004; Thomas, 1997) have shown that there is often increasing pressure for a disabled mother not to ask for services or supports that would assist their mothering through a debilitating need to be perceived as 'capable'. This points to the damaging effect that professional scepticism can have on the self-worth, and resulting feelings of ability, of the mother. If the mother feels constantly undermined and humiliated, the consequences upon her self-esteem can be devastating. This form of psycho-emotional disablism (Reeve, 2012, 2014) is cruel and exhausting, and is a colossal drain on the limited energy resources of any new mother. In my experience, this has led to me feeling that I am unequivocally unable to cope with the responsibilities of motherhood, and therefore unable to reliably handle my own child, as I have tried to illustrate in my narratives. I feel the grip of this sensation starting to weaken as I explore and expose the ableism tied up in constructions of mothering that emphasise the physical dexterity of mothers.

However temporarily uplifting and empowering these narratives of choosing motherhood are, some studies (Callus & Azzopardi-Lane, 2016; McFarlane, 2005; Prilleltensky, 2003; Thomas, 1997) show that the experience of pregnancy and early mothering for disabled women is treacherous, requiring inordinate amounts of iron will and determination. The emotional labour of acting in defiance of family, friends and professionals is a crucial factor threatening to obscure and dampen the transition to motherhood for many disabled women. Researching the phenomena of disabled mothering has shown me that I am unfortunately not alone in the hostile responses from certain individuals in the medical profession. Studies of disabled pregnant mothers-to-be confounded this perception (see Crow, 2003; Prilleltensky, 2004; Skinner, 2011; Thomas, 1997). All of these studies show that disabled women are routinely objectified, marginalised, and treated with a toxic mixture of scorn, disbelief and distaste. Often disabled mothers are seen as selfish and reckless for bringing a life into this world when it is a common misconception (Baum & Burns, 2007; Prilleltensky, 2003; Wates & Jade, 1999) that they can barely look after themselves, however true or false that might be.

As Liz Crow (2003, p. 3) states in her presentation to the Department of Health around the provision of maternity services to disabled women:

> When I'm on the outside needing to get in, what I see is a lot of people missing the point. My being on the outside is not about me, but about them. It's about the assumptions, and the ways of working that exclude whole groups of people. Tackling that exclusion, by introducing inclusive practice, is not about making 'exceptions' or meeting 'special needs' (It is only when they are not provided for that needs become special). In maternity services, inclusion is about achieving a start where I can primarily be *pregnant*—not because I am the same as non-disabled pregnant women but because my needs are just as integral to planning and working practice as theirs.

Crow's point here is that, as a disabled woman, she is largely not provided for in maternity services and thus rendered invisible, but as soon as she alerts her presence to them she becomes a 'problem' in need of 'special' needs. In her own words, she becomes "centre stage" (Crow, 2003, p. 3). We can apply her statement, 'it is only when they are not provided for that needs become special' to a range of institutions and social practices, and it has specific salience here. If society was open to the diverse range of people who mother I may have felt more secure of my impending motherhood as the range of adaptive solutions may have been more readily accessible. Sadly, as it presently stands, disabled women are not on the list of society's idea of 'good' mother material. This is a stark reminder that reproductive liberty does not have the same significance for every woman. Admittedly there are concerns about the impact that a loss or malfunction of a limb or energy fluctuations has on a person's ability to mother, as my narrative shows. But how much of this is due to practical concerns (which in a truly inclusive society would be provided for) and how much can be attributed to internalised ableism—the product of living in a disablist world?

This is where the provision of adequate and affordable support comes in. Access to goods and services in the consumer market can be a lifeline for many disabled women, and can provide additional networks of support in a society that prizes self-reliance. Where this support is lacking it can cause detrimental effects to the psycho-emotional well-being of the mother, as exampled in my own experience:

> 12th June 2016. I pondered and planned in careful and considered detail throughout my pregnancy, purchasing the softest clothes and the latest gadgets; but everywhere I looked there were obstacles lying in wait. Pushchairs are not designed with the disabled body in mind. I trawled through websites and browsed countless shops, but the responses were the same—'we don't have anything for you I'm afraid'. Nappy changing also created a wave of fear; one thing that parents will have to perform relentlessly, and there are very few effective solutions on the market to aid someone like me. Baby-wearing, which I was keen to do, was only possible with someone else to help attach her to me. It became conspicuously clear that I would not be able to mother independently and that concerned me greatly. I have never felt more disabled than I did during my pregnancy. This sense of trepidation and unease perpetually gripped my throat, tight, strangling my joy. I desperately tried to think positive and to hold on to the wisps of happiness and excitement that this new life was bringing, but I also felt it was my responsibility to be realistic and practical. With this in mind, I searched endlessly, and fruitlessly, for gadgets, devices, anything that may make my life as a mother smoother and more manageable. It became clear that if you don't

> fit into the narrow stereotype of a mother-to-be then there is nothing for you.

9. Adaptations and Accommodations: A Lifeline, or Coercion to Ableist Normativity?

Although there are a number of adaptive solutions available to aid disabled parenting, these are scarce and often difficult to access. They are also often beyond the financial means of the families who could benefit the most from them. I enlisted in the private help of a professional doula, but as she was unfamiliar with disability issues she was unable (or unwilling?) to help. According to a survey carried out by the Disability, Pregnancy and Parenthood International (DPPI) in 2011, more than 70% of disabled parents were not aware of any sources of information or adaptive equipment (DPPI, 2015). Additionally, the results from this survey indicated that both social care professionals and disabled parents "struggle to find appropriate resources on disabled parenting" (DPPI, 2015, p. 1), and that the quality of the support that they did receive was inadequate. One notable exception to the lack of resources is the organisation Through the Looking Glass (2018) in the US, which was founded in 1982 to help families in which a child, parent or grandparent has a disability or health-related issue. A similar organisation, Remap.org, is available in the UK, creating adaptive solutions for disabled people throughout their lives. Another site, DisabledParent.net, is largely aimed at wheelchair users, thus ignoring or side-lining other disabilities. The site features products that disabled parents have made themselves, reinforcing the idea that disability is the responsibility of the individual, akin to the medical model that many disabled people have worked hard to dispute. The DisabledParent.org is another similar example. The website points out things to look for when shopping on the mass market for equipment that can be adapted to suit individual needs, such as prams/buggies that are lower to the ground for ease of access etcetera. It does not give any suggestions for specific equipment and, again, suggests that this is the responsibility of disabled parents themselves. The website actually states:

> Parenting positively changes the lives of disabled individuals. It presents an opportunity for a *normalized life* where you get to parent like your nondisabled peers. Your journey comes with great satisfaction for being able to surmount the challenges of parenting with a disability. (Disabledparent.org, 2017, emphasis added)

This conceptualises a stated desire for parents to *overcome* the disabling barriers of a hostile society through their own actions by mimicking non-disabled people. All sites reviewed assume that there will be someone else in the house with you to do some baby care tasks, contravening the strong cultural imperative of self-sufficient mothering. Compensatory measures set disability as being the fault of the individual, and as having nothing to do with a restrictive society. In effect, the search for adaptive solutions promotes the disabled mother's assimilation into ableist norms.

10. Concluding Remarks

According to Shildrick (2002, cited in Mitchell & Snyder, 2015, p. 4), certain countries in the western world "are making tremendous strides towards the formal integration of the rights, obligations, and expectations of normative citizenship" for disabled people. However with the case of reproduction and disabled motherhood in mind, these changes are not paralleled by a dramatic enough shift in public attitudes to disability. By engulfing disabled people within the depths of normative citizenship, it is becoming increasingly difficult to "recognise (our)selves outside of the values, needs and desires preferred by the market" (Mitchell & Snyder, 2015, p. 4). We must therefore recognise the danger inherent in being subsumed, *gratefully*, into the seduction of compulsory ablebodiedness with its punitive principles, instead of challenging the very foundations that this disablism rests upon.

As I alluded to earlier, many mothers are complicit in perpetuating the restrictive and prohibitive ideal of the 'good' mother. Faced with overwhelming depictions of themselves in the social imaginary as inadequate and deficient, it can take extraordinary levels of emotional and physical labour to try to perform the idealised mother role, and even more to resist and refuse such limiting narratives and forge new connections and resources for enacting motherhood. And so it is that countless disabled mothers, myself included, push themselves to achieve an able-bodied articulation of idealised motherhood. Through the lens of ableism, we can see that, by trying to conform to standardised notions of the 'good mother', many disabled mothers are trying to pass or morph ableist ideals when actually we need to break free from this suffocating oppression. All compensatory measures set the 'problem' of disability up to be as individual issue, one that needs to be corrected by assimilating disabled people into ableist norms. I read about disabled women trying—and being praised for—doing mothering in normative ways, in spite of the emotional and physical energy that this takes. These stories tend to deny the unique knowledge that disabled mothers have, incorporating *inter*dependence, cooperation and connection. The very notion of 'overcoming' disability is a dangerous preoccupation, as it concerns itself with disability disavowal. This splitting off of disability in an effort to return to a historically unstable version of 'normality' denies the importance and validity of owning a disabled existence. Future research is essential to address how products, services and supports could be expanded and energised in a way that absorbs and reflects the needs of a diverse society, *in*clusive of disabled mothers.

The atypical and creative ways in which disabled women perform motherhood are not recognised, provided for or even acknowledged in the consumer market of products and advice targeted at mothers. Bravery, courage and tenacity should be found in the ways that those three simple words: 'I need help', are asked in a society that demands and enforces independence in mothering tasks.

On the surface opponents to disabled mothering argue that the mother (inevitably) could not cope with the demands of childrearing, and that there is a fear that the 'biological defects' could be transmitted to the child. This, they say, would constitute irresponsible mothering. But I sense there is something deeper at play here. I argue that by admitting us in to the sacred hallow of motherhood, this threatens to destabilise the social construction of disability as inherently less than, incapable, *in*valid. The Mother is an esteemed figure in society, and conflating the two stereotypes further weakens the precarious binary. It engenders a deep-seated anxiety in "those who are able to broadly align themselves with the illusory standards of the psychosocial imaginary" (Shildrick, 2012, p. 32). Disabled motherhood creates fear because it exposes the instability and the futility of aspects of individualism and the incessant race for perfection that it is grounded upon. It exposes as futile the hundreds of products on the market aimed at 'making you a better person, inside and out'. It does this by dispelling the assumption of the relegated Other—the disabled—to which able-bodied society can compare themselves and feel relieved. Capitalist society needs to continue to promote the insinuation that all of us are never good enough in order to further the plethora of goods and services in the consumer market to aspire to perfected, unstable, and unreachable 'norms'.

Acknowledgements

The author would like to extend thanks to the Economic and Social Research Council (ESRC) who funded her PhD. Grant code ES/J500215/1.

Conflict of interest

The author declares no conflict of interest.

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COGITATIO

Social Inclusion (ISSN: 2183–2803)
2019, Volume 7, Issue 1, Pages 124–135
DOI: 10.17645/si.v7i1.1717

Article

Dressing a Demanding Body to Fit In: Clean and Decent with Ostomy or Chronic Skin Disease

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Submitted: 17 August 2018 | Accepted: 1 October 2018 | Published: 31 January 2019

Abstract
This article discusses what kind of strategies people with a stoma or various chronic skin conditions, such as psoriasis or atopic dermatitis, use to find clothes that fit and enable them to fit in. Based on qualitative interviews in Norway, we study how they manage to dress with a demanding body, a poor market and limited economic resources. This includes describing how purchases take place, which clothes fit, how much clothing is needed, and which laundry practices are used. Their main strategy was to reduce the requirements for their own appearance rather than to cleanliness and body odours. If they were unable to appear appropriately dressed, as a minimum odourless and stain free, they reduced their participation in social life.

Keywords
apparel; cleanliness; clothing; consumption; dermatitis; disability; laundry; odour; ostomy; psoriasis

Issue
This article is part of the issue "People with Disabilities: The Overlooked Consumers", edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

1. Introduction

We all have to be dressed; however, some bodies are more difficult to dress than others. Having clothes that fit the body as well as the occasion are central to being able to take part in social activities. About 15% of the population worldwide lives with disabilities, and that number is increasing due to an ageing population (WHO, 2011). Having a disability can increase the chances of experiencing physical restrictions and social barriers in everyday life. Here, we use the word 'disability' in its wide and simplified meaning, as any "permanent injury or chronic illness" (Grue, 2015, p. 27).

Previous studies have shown that the clothing market for users with disabilities is poor, and in some cases almost non-existent, especially for consumer groups with physical disabilities (Bjerck, Klepp, & Skoland, 2014; Freeman, Kaiser, & Wingate, 1985; Thorén, 1996). Products poorly designed and not fitted properly for the wearer not only can make life difficult but also lead to unpleasant or even painful and unhealthy conditions. Mass produced apparel available in clothing stores is designed for the non-disabled user and is difficult to adjust to special needs; thus, it seldom satisfies the technical and social needs of many disabled users (Kabel, Dimka, & McBee-Black, 2017; Kratz et al., 1997). Clothes are important for self-esteem and influence the opinions of others (Kaiser, 1997). Indeed, the appearance of clothing is important; but equally important is that it must not be dirty or smelly (Klepp, 2007).

The purpose of clothing is to conceal the body and make it socially acceptable (Lamb & Kallal, 1992). More, however, is required from clothes to conceal a body that does not conform to current beauty ideals, than to conceal an "ideal body" (Entwistle, 2000). Deviating bodies are thus both physically and socially harder to dress. Previous research has shown that consumers with disabilities use two main strategies. In some occasions, they dress so that the disability is minimally visible, while in other contexts, they dress so that the body functions optimally (Bjerck et al., 2014). These two strategies are often contradictory, and the one chosen depends on the occasion. It is also an important norm for people with disabilities to accept their bodies as they are, which contrasts with the norm of wishing to normalize the body (Klepp & Rysst, 2017).

People with disabilities have lower average incomes and may have extra costs resulting from the disability (WHO, 2011, p. 10). This applies also to clothing: people with some disabilities require more resources to achieve the same level of appropriate dressing as non-disabled people. Because of higher costs, people with disabilities are likely to be poorer than non-disabled people with similar incomes (WHO, 2011).

Previous studies on clothing consumption do not combine this economic aspect with disability and social inclusion in a way we want to do. Many of the studies have also focused on physical disabilities, especially wheelchair users, and we want to study consumer groups with a more common diagnosis. In this article, we focus on two conditions that are among those that cause the most extra clothing costs in Norway: psoriasis and other chronic skin conditions, and people with ostomy. This article discusses what kinds of strategies people with these disabilities use to find clothes that fit and enable them to fit in. Specifically, how do they manage to dress to fit in with a more demanding body, a poor marked, and limited economic resources.

We will first give the theoretical starting point for our research as well as some background information on the consumer groups we study. This is followed by a section on our methodology, which included qualitative interviews conducted in Norway in 2018. The results section shows how the disabilities affect our informants' everyday life, their clothing acquisition and maintenance practices and the economic aspect of their clothing consumption. This is followed by a discussion on how these aspects are managed and which strategies are chosen to fit in. We conclude with a discussion about the consequences of our findings for social inclusion. We then give suggestions for future research areas.

2. Background

In Norway, people that have extraordinary clothing costs due to illness or medical condition are entitled to receive a monthly support to cover these expenses. To date, qualifying for this support means that the expenses have to be documented for a minimum of three months and have to exceed a specified sum compared to normal costs[1] (NAV, 2018). This documentation practice has been criticised (Proba, 2017). Some of the expenses are difficult to document through receipts, such as the additional wear and tear of clothing or the need for extra laundering. For many individuals with various medical diagnoses, it is also difficult to collect receipts and to systematically document the extra costs over such a long period of time. It also creates the potential for inequality based on income, since those with low income cannot necessarily afford the clothing they would need to buy to qualify for the support, while those with a higher income can buy all the necessary products and easily document the extra costs (Proba, 2017). Therefore, this system is now under evaluation to see if the application and qualification process can be simplified. This article is based on a project that evaluated the extra costs for some diagnosis groups that commonly receive the support (Roos, Laitala, Klepp, Austgulen, & Borgeraas, 2018). The groups were chosen based on statistics on diagnosis codes that commonly receive support for extra clothing costs.

3. Theoretical Framework

Disability studies have gone through a shift in focus from medical model towards social constructions (Berghs, Atkin, Graham, Hatton, & Thomas, 2016; Grue, 2015). The medical model reduces all the aspects of disability to bodily impairment, which requires medical treatment. The social model gives a voice to the people with disabilities. People with disabilities are seen as a politically and economically oppressed class in a Marxist theoretical framework (Grue, 2015). However, Tom Shakespeare, a sociologist working in disability studies, suggests that rather than dichotomizing these opposing models, disability should be understood as multi-factorial, including biological, psychological and social aspects; thus, disability does not just result from social oppression. He proposes that "[w]e need to take account of all the factors, and intervene at all the different levels to benefit and include disabled people" (Shakespeare, 2018, p. 21). We follow Shakespeare's recommendation, and use perspectives that include biological, psychological and social aspects of disability in our research.

Disabilities and various medical diagnoses themselves can make it more difficult for people with disabilities to be socially accepted. This is in line with Goffman's (1986) theory of stigma, in which the stigmatised attribute causes the person to be looked upon as abnormal and then rejected. Goffman discusses how a person with a stigma tries to control the information about it. He uses the word 'passing' to describe a person who manages to hide the stigma and, thus, pass as a person without the stigma. Goffman does not discuss clothing as a technique of information control, but clothing can be used to facilitate acceptance (Entwistle, 2000). Not only is the body itself subject to taboo but so too are the body's secretions (Douglas, 1984). Such substances as urine, sweat, mucus, tears, breastmilk, menstruation blood, faeces, discharges, pus, dandruff and semen are often considered culturally problematic (Mauss, 1979). Clothes constantly

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[1] Currently minimum limit is NOK 678/month, about EUR 71 or 84 US dollars (exchange rate of September 2018).

become ‘contaminated’ by them, and this contamination may be visible in the form of stains, may be invisible, such as bacteria or may be sensed through other means, such as smell or touch. Today, bodily malodours are especially considered socially stigmatising (Classen, Howes, & Synnott, 1994; Frykman & Löfgren, 1994). Being unable to control the body’s fluids is a stigma affecting the way a person is perceived.

Entwistle (2000) argues that clothes act as the body’s boundary to the world. They constitute a border between the individual and society. To maintain a clear boundary, we must not only have clothes but clean ones (Klepp, 2003, 2005; Shove, 2003). Cleanliness norms for clothes are complex and vary with age, gender and class. Rules attached to the cleanliness of women’s clothes are the strictest (Klepp, 2007). How much is demanded from clothes, or how strict the clothing norms are, depends both on how much the body is subject to taboos and on the social situation (Klepp, 2007). To some extent, these norms seem to conform to the norms connected with decency. This is understandable, since both are related to the way the body is made socially acceptable. Lurie writes that cleanliness “is usually regarded as a sign of respectability or at least of self-respect” (Lurie, 1981, p. 13). For example, one of the aims within charity work is to provide people with clean clothes because that contributes to returning dignity to the recipients (Larssen & Bry, 2001).

Various disabilities and conditions require extra consideration for selecting clothing, and cause additional costs related to wear and tear. Below, we give a short background for the disabilities this article focuses on.

3.1. Psoriasis, Atopic Dermatitis and Other Skin Diseases

Psoriasis and atopic dermatitis are chronic inflammatory skin diseases. In both conditions, skin may appear red, inflamed, peeling, cracked, blistered or pus-filled, but psoriasis has the additional characteristic of a thick patch of white scales (WHO, 2016). Lesions cause itching, stinging and pain. Both skin conditions are common (Siegfried & Hebert, 2015; WHO, 2016), and atopic dermatitis affects up to 20% of children and between 2.1% and 4.9% of adults worldwide (Barbarot et al., 2018; Nutten, 2015).

Some individuals with psoriasis develop chronic, inflammatory arthritis (psoriatic arthritis), which leads to pain, swelling and stiffness in joints and tendons. The disease can affect the hips, shoulder and elbows, as well as small joints such as those in fingers. Psoriasis has also other significant comorbidities, including cardiovascular diseases, metabolic syndrome, inflammatory bowel disease and depression (WHO, 2016).

Hidradenitis suppurativa (HS) is another chronic skin condition, which is an inflammation of the sweat glands. HS can become a painful, long-term skin condition that causes abscesses and scarring on the skin. An outbreak causes pain, fluid bumps and bad odours.

Chronic urticarial (CU) is also called ‘hives’ or ‘nettle rash’. CU is an allergic condition of the skin, which is characterized by a skin rash, notable for its dark-red, raised, and itchy bumps that may also burn or sting (Sachdeva, Gupta, Amin, & Tahseen, 2011). It affects 15–20% of the global population once or more during a lifetime. In most cases, chronic hives occur for 1–5 years, but it may last for several years. Psoriasis, HS and CU are more common in women than men.

Several studies have reported that psoriasis has a negative impact on quality of life (QoL; Augustin, Kruger, Radtke, Schwippl, & Reich, 2008; de Korte, Sprangers, Mombers, & Bos, 2004; Moradi et al., 2015; Weiss et al., 2002; Zachariae et al., 2002). Based on a large European survey among psoriasis patients in seven countries, Dubertret et al. (2006) showed that the biggest problem among these patients was the choice of clothes, followed by an increased need for body wash and an increased amount of doing laundry and changing clothes. Over 40% of respondents reported that these activities were influenced by their psoriasis to a large or very large extent. Those with a larger proportion of the body affected by psoriasis reported major problems.

Some scientific articles discuss the extra expenses associated with psoriasis and atopic eczema (Dubertret et al., 2006; Navarini et al., 2010). Some ointments increase the need for laundry, new clothes and new bedding more than other ointments (Poyner, Wall, Adnitt, & Menday, 1999). A study of German psoriasis patients showed that increased laundry costs were 28 euros[2] per year, but the study does not indicate the costs included in the estimate (Sohn et al., 2006). It has also been reported that the time spent on the treatment of psoriasis and on doing more laundry add significant cost to patients when calculating cost in terms of time lost (Mustonen, Mattila, Leino, Koulu, & Tuominen, 2014). Most studies focus on treatment costs, and they rarely include increased clothing costs (e.g., Navarini et al., 2010); if they are included, they are given together with other costs (Berger, Ehlken, Kugland, & Augustin, 2005). Many calculate costs at the national level rather than at the individual level (e.g., Ellis et al., 2002).

3.2. Ostomy

A stoma is an artificial opening in the abdominal wall. The end of the small or large intestine, colon or ureter is connected to the surface of the abdomen to provide an alternative channel for faeces to leave the body. People with ostomies have pouches attached to their sides where the bowel contents are collected. The most common underlying conditions resulting in ostomy surgery are cancer in the colon or bladder and inflammatory bowel diseases (IBD), such as ulcerative colitis or Crohn’s disease (Brown & Randle, 2005). The stoma opening connected to the small intestine is called an ileostomy, while in a colostomy, the soma is connected to the large intes-

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[2] Equivalent to about 33 US dollars in January 2006.

tine or colon. A stoma that diverts the urea is called an urostomy. In addition to health problems connected to the underlying causes for ostomy, about half of the people who had had ostomy operation also develop hernias (Cima, 2018).

Numerous studies on life quality after an ostomy operation point out several potential problems. Patients reported that the operation altered their body image, had a negative effect on their social life, sex lives, limited their choice of occupations because of the possibility of leakage, and forced them to adjust their diet and clothing choices (Brown & Randle, 2005; Gooszen, Geelkerken, Hermans, Lagaay, & Gooszen, 2000). None of the studies given in literature review by Brown and Randle (2005) on living with a stoma focused specifically on clothing, including the maintenance and economic aspects. Clothes should support the pouch, while not putting too much pressure on it (Proena & Rydelius, 2015). The studies that do focus on extra costs are related to the direct costs of the ostomy equipment (Coons, Chongpison, Wendel, Grant, & Krouse, 2007); they do not include the extra costs related to leakages and laundering.

4. Method

We contacted two patient organizations, the Psoriasis and Eczema Association (PEF) and the Norwegian Association for Stoma, Reservoir and Gastrointestinal Cancer (Norilco), who recruited informants to our study. In addition, one informant was recruited through private networks. We asked the organizations to find up to five members who present a variation in the diagnosis groups which the organizations represent. The organizations arranged contact with our informants so that we did not have to collect or store any personally identifiable information in order to ensure complete anonymization of the data. We originally wished to collect data through group interviews. This was possible with the PEF members, but because of the busy schedules of our informants from Norilco, those interviews were conducted individually.

PEF facilitated the group interview by inviting five of their members to the meeting, four women and one man, who represented different but related diagnoses. The man had chronic urticaria, a diagnosis that has fewer consequences for clothes; therefore, he had less to say. The four women presented the following diagnosis: psoriasis, psoriasis arthritis, atopic dermatitis and allergies, and HS. All of the informants in this group were around middle aged, in their forties and fifties, except for the person with psoriasis arthritis who was already retired. The informants showed a great willingness and ability to be open and honest about intimate and even unpleasant topics. This interview took place at PEF's main office and lasted two hours.

We interviewed individually three people with ostomies who represent rather different groups. The first was a young woman in her early twenties who had a temporary stoma due to Crohn's disease. She had had the stoma for only a few years, and was waiting for her operation to have a permanent colostomy. Even though she was a relatively new stoma user, she had more knowledge about the topic because she had participated and talked with others in a similar situation in a different project. Our second interview was with a retired man who had two stomas, ureostomy and ileostomy, which is rather unusual. He had had them for a long time due to cancer, but he had learned to live with them. He pointed out that the situation was better now than when he was living with the painful cancer. These two interviews were conducted at the university and took just over an hour.

The third interview was conducted by phone and took a little over 20 minutes. The informant was a woman in her early fifties; she had had a stoma for over 30 years due to Crohn's disease. She was working full time and experienced less stoma-related problems than the other two informants. This interview was based on the notes from the first one, and we discussed on how her experiences were similar or different compared to our first informant.

Discussions during these qualitative interviews were structured around clothing practices, and we used an interview guide listing all the basic clothing and textile items that can be affected by the conditions, including shoes and bedlinen. We asked the informants to describe their clothing acquisition, how they used the clothes during various occasions, how often they washed them and with what temperature and how often various items had to be replaced due to wear and tear. We also asked specifically which clothing consumption areas they considered to be problematic, and if there had been any changes as their condition developed. The aim was to find out which additional clothing costs the informants had when compared with non-disabled users. The interviews were conducted during May and June 2018 in Oslo, Norway, and all our informants live within a 70km radius from the city. We recorded the conversations, and after the meetings, the interviewers wrote summaries. These were sent back to the associations so that the informants had the chance to comment. We analysed the data by organizing the results based on clothing and textile types and the occasions of use; we then compared the experiences (see more details in Roos et al., 2018). This way, we found which areas were problematic to our informants. These themes are discussed by topic in the results section of this article. For this article, quotations are translated from Norwegian to English by the authors.

We have chosen to collect and analyse material as examples of the problems and solutions that the diagnoses give and not to focus on the individual informants. Therefore, the informants are not presented with their name and age in the text. Where we believe personal information such as gender is relevant to the interpretation, we have mentioned it with a citation. This study is exploratory in nature and based on a small number of respondents recruited by patient organizations; therefore, the results cannot be generalized to apply to all people with similar conditions. It does, however, provide a starting point for discussing topics that have not yet been researched.

5. Results

5.1. Clothing and Acquisition

The disabilities may affect what kind of clothing fit and how purchases can take place. First, we look at the purchase situation and then describe how the disabilities affect which clothes are suitable.

5.1.1. Purchase Situation

Clothing production today is dominated by ready-made manufacturing. This means that clothes are not adapted to individual users but are made to fit standardized measures. They can be bought in stores or through mail order; both options provide the possibility to try them on. Trying on the clothes ensures that the clothes fit the body and that they feel comfortable to wear, but it also ensures that the buyers like the way they look when wearing the garment. The option of trying on clothing was not available for many of our informants.

Informants with psoriasis worry that different substances will be left in the clothes after they try them on. One informant said:

> You get so tired and just despair, because you cannot go in and try on clothes that someone else might try after you. There hangs a kilo of dandruff and blood stains and a bit of pus and dirt…[and] then you may have a bloody back that seeps out.

This applies to underwear, jeans, shirts and blouses. One of the informants says she has done a lot of mistake purchases:

> When your skin looks like a meat cake, you do not want to go into a fitting room and put on clothes that others may wear afterwards. Then I take it on me [she shows how she puts the clothing item in front of her body to evaluate fit], and then it looks like it fits, but then it does not.

For ostomy poach users, trying on clothes can be difficult because they are afraid of leaks and also that the poach may be seen:

> The salespeople are trying to assist and come in and help. I do not think that is okay because I'm so afraid that they'll see the pouch and so if they know what the ostomy is, they'll say, 'No you are not allowed to try it on because it is so easy to get a leakage'. And it's also a horror scenario to get leakage while trying on clothes, or that the pouch gets torn off. It does not really happen, I mean it has never happened to me, but you get so anxious about it....At the same time, I have to try on the clothes to see that they suit me well and that fit over the ostomy poach.

At the same time having an ostomy makes it more difficult to find clothes that fit. Clothes are used to conceal the pouch, and this is more difficult in situations like trying on clothes in fitting rooms. It is problematic due to the potential of ruining the clothes, but also because of the fear of ruining them. In addition, our informant is concerned about revealing herself as a carrier of stigma.

5.1.2. Requirements for Clothing and Fit

There are some specialty products for people with disabilities, such as Velcro shoes for people with joint problems and special lingerie for ostomy with a pocket for the pouch, but our informants used these products very little. For example, they choose not to wear special underwear because it is expensive and cannot be washed at high temperatures, but also because it is not 'normal'. One of our ostomy informants uses mainly high-waist pants and a longer sweater or an over jacket. She buys clothes in regular stores, as she would rather not have to use special products in order to live the most normal life she can without feeling like a patient.

For all stoma users, it is important that there is enough of space under the clothes for the pouch. Pants with a low waistline can be beneath the pouch, and those with a high waistline can be placed over the pouch. A larger problem occurs if waistline is on the pouch and thus prevents it from being filled. These kinds of pants with a semi-high waistline are the most common today. Our informant who worked in project with other people with ostomies explained: "I have also heard that a lot of people buy maternity pants and sew the waistline so that the pouch sits where it should be". She solved the problem herself by wearing dresses or skirts combined with tights that are bit bigger than her own size to keep the poach in place.

Psoriasis arthritis gives reduced mobility, and the clothes need to be easy to put on and to take off. Thus, wearing clothes and shoes with small buttons, loops, laces or hooks was out of the question. One of our informants had problems with multiple joints, including deformed feet, which led to the need for specially made products, such as supportive shoes and insoles, but also that shoes were worn out fast. She had made a lot of mistake purchases:

> You try the shoes on in the store for two seconds, and that day the foot is in that lease and then the other day you have swelling and maybe another shape in toes, and then, 'what, have I had these shoes on me'. Today I cannot get them on at all. It varies greatly. Therefore, I could start a shoe store.

5.1.3. Sensitivity and Materials

The choice of materials is characterized by the demands of frequent and hard washing, and by the requirements related to the informant's desire for comfort.

Consumers with psoriasis and other eczemas have sensitive skin, and, therefore, they prefer soft clothes. Cotton, soft merino wool and viscose (also called bamboo) were preferred. They could not use the most common underwear because it has sewn rubber bands, and often decorative elements which itch, such as lace. It was also obvious that all labels were removed.

Consumers with ostomies use cotton as much as possible because it tolerates harsher laundering, whereas synthetic fabrics as well as viscose become quickly unsightly by the hard washing. The few clothes our youngest informant had in wool were for the most part valuable clothes, such as handmade clothes made by older relatives and her bunad. Bunad is a Norwegian folk costume owned by 66% of women and 21% of men, and it is used at different festive occasions (Klepp & Laitala, 2018). It includes woollen embroidery, and other expensive fabrics, which are challenging to clean. When our informant used the valuable garment, she was especially attentive and careful so that it would not be damaged by stains. To wear it was, therefore, demanding.

5.1.4. Replacements and Changes

Many of our informants spoke about frequently washing clothes, which implies an increased need to have enough clean clothes available. Our retired informant with two ostomies told the following: "I have usually a set of clothes in the car, but I still have anxiety, if I'm getting leakage here and it's far to the car, so I have to walk with it, and it has happened several times". It is important to have clothing available at any given time.

Another problem that increases need for clothing is changes in weight. The informants spoke about weight changes related to cancer, problems with digestion or various medical treatments, such as cortisone and chemotherapy. One of our informants lost and then quickly regained 35kg, which affected which clothes fitted. It is not farfetched to think that patients who experience weight changes may have to keep several wardrobes of different sized clothes, and then alternate between them when needed. Even though this process is possible, it is not so easy in practice. As our youngest informant with ostomy explained:

> You may have to wear clothes in bigger sizes again, and then you have a new round of medication….You may be a little optimistic when you are sick, thinking that now I'm not getting sick again and I can throw these clothes away. I do not want to have them because they remind me of a bad episode as well. Because you get memories connected to your clothes too that are part of your personality.

Getting rid of clothes which no longer fit and which remind the informant of bad memories highlights the social and aesthetic aspects of the clothes. The quotation clearly shows that clothes are more than just a way of hiding the body. However, in the interviews as a whole, this aspect is not emphasised. The practical and material aspects of clothing are highlighted more.

5.2. Laundering

Both of the conditions cause secretions from the body, and skin conditions require additional use of skin care products, which can make the clothes and bedlinen dirty. Both conditions also set requirements for how the laundry should be performed to meet today's cleanliness requirements.

5.2.1. Oily Lotions, Flakes and Stains

The main reason for the extra wear on clothes and bedding for people with psoriasis is due to daily use of greasy creams and ointments. All of the informants said that weekly washing of bedlinen was required. Bedsheets, lingerie and other textiles that came in contact with the creams were washed at least 60°C. Ordinary washing in a machine was often not enough; instead, the textiles had to be rinsed beforehand to remove some of the grease so that it was not collected in the washing machine and potentially damage it. Daily use of a washing machine was common. Some also mentioned that they had to wash the machine between the laundry cycles to remove grease. Eventually, the clothes started to get a rancid smell from the ointments, which did not go away in the wash.

Underwear, nightwear and towels had to be washed after each use: "Nightwear is washed every day because if you have so much ointment on you, it gets so sticky you don't want to wear it. It is gross". The washing frequency for regular clothes varied more because the creams used during the day are less greasy. In bad periods, more severe ointments were used, and the informants attempted to use older textiles, which were then thrown out when a better period started.

In addition to the lotions, there were problems with stains of blood and pus. As one of the informants with psoriasis explained: "I had to be in the shower to take off my clothes. They were stuck in the wounds". Another big problem was her flakes: "I never use black pants, because they become white on the inside". It is difficult to estimate how often clothes are washed, but the informants thought they washed jeans after two to three days, which is twice as often as the average in Norway (Laitala, Klepp, & Boks, 2012). However, the washing of clothing tops did not vary much from the usual, since they were washed after one to two days. The washing temperatures were close to the ones used by other Norwegians (Laitala, Klepp, & Henry, 2018).

Several people with psoriasis and eczemas also have allergies. This means that various chemicals in clothing and detergents could be a problem. In addition, the skin reacts more easily to physical irritation from the clothes. There was a conflict between the need for soft clothes and their problems with chemical products, such as fabric softeners. The choice of detergents varied. Those with allergies used perfume-free agents for sensitive skin, while others tried to use the most effective and perfumed detergents to hide possible smell.

5.2.2. Leakages, Smells and Spills

Informants with ostomy have to prevent leakages, which is more important in public settings: "You are much more aware of the potential leakage when you are out among people, because it is subconscious, that you just keep thinking about it". It is possible to use larger pouches, but, at the same time, it will make the pouch more visible and inconvenient. An ileostomy pouch is emptied in the toilet, but it can be difficult to do this without splashing the clothes. One of our informants assumed this was a problem especially for older or less mobile people than she was.

Our informants experienced most leakages at night because they have less control while asleep. Thus, nightwear needs to be cleaned often and must withstand hard washing. Ideally, all clothing that could be exposed to leaks (lingerie, nightwear, tights, pants, dresses and skirts) should withstand at least a 60ºC normal wash and dry cycle. In practice, the clothes could not withstand this, so our informants usually solved this by washing the laundry according to the care instructions and at a higher temperature after leakage. Our youngest informant was especially aware of this: "If there are smell stains on the leaked valve, then I wash it at once at 90 degrees".

Our informant with HS lived on disability benefits. Her HS outbreaks occurred mostly in the armpit and were fierce: "It seeps, flows pus. It smells so rotting". She said that she "smells the malodour before noticing that the lump has ruptured. Then you cannot sit in a gathering, are you crazy, it stinks so badly you think you may pass out....It's so embarrassing, especially the smell, because you can be perceived as unhygienic". In addition, smell is perceived as something that is difficult for others to overlook or get used to. Odour can, therefore, be a challenge for ostomy users as well, either because it actually smells or because they themselves are anxious about the possibility of it smelling. Our youngest informant with stoma explained the following:

> It is similar to feeling as if you have not brushed your teeth one day, and you talk to somebody, trying to keep a little distance to them. That's how it is, but only constantly all the time when you're out among people.

Even an ordinary, slight smell of the body can be stigmatising in our time (Klepp, 2005). To smell as bad as our informants sometimes experience is so obviously stigmatising that even the fear that it will happen contributes to their clothing practices. Preventing leaks is a part of the routine to hinder this, but it also affects many other aspects of daily life.

5.3. Clothing Problems and Everyday Life

Being well dressed and wearing clothes without stains and odours are also important prerequisites for taking part in various social activities. Our informant with atopic dermatitis worked within healthcare and had to wear a white uniform. She told of her experience with clothing:

> I ended up having to change the uniform several times a day because my back bled and it bled through and was visible. It was terrible. I entered into an agreement with my colleagues that they had to tell me when it went through. But it was not a profession I could have. I had to work more even at work.

The informant who spoke most about everyday problems was a young, active student. She said the following: "With the ileostomy, just being in the park with my friends and barbequing is scary because there is not always toilet available". She had experience before:

> It has actually happened once. I got a leakage and did not get into the bus, and there was no taxi that would have me either, and then my aunt from another city had to come and pick me up. So there I was standing in the city like thinking 'Help!'. Then she came fortunately, but it was not very pleasant to stand there waiting.

The experiences with ostomy were worst at the beginning, as described by our retired male informant:

> It was this fear of leakage and the whole package. I was even anxious about the fear of leakage, and then I had to always have a travel route planned where I knew there were opportunities for a toilet....I started to have a small bottle in the car if I had to pee and had no place to go and brought some extra clothes and all that. Then I set up a travel route so that I knew there was a gas station or something on the road so I could plan a little ahead. So those years were very difficult, I have to say, and it was very unusual that you should wash laundry so often and so on. There were some processes to get used to.

His strategies to live with the ostomy involve controlling where he is and how he travels from place to place. He must always have clothes available to change into. Still, the anxiety is present.

Exercise poses special requirements: "You do not work out when you are like that. You do not go training with an outbreak". Informants with skin conditions have something else to think about; they are in pain and worry sweating may worsen the situation. For people with ostomies, the challenges are more constant, including having access to a toilet to avoid leakages and to handle the odour, which can be a problem, along with the risk of a hernia:

> I'm not a very sporty person and it's partly related to the hernia. I can go walking and things like that, and it is possible to empty [the poach] in the forest, but I prefer not to, both for my own sake and for others. You try to avoid it. I rather stay at home and watch Netflix than get out to the woods.

These examples show how our informants' conditions affect their daily life. It includes their choice of occupation, their leisure time and physical activity, as well as their interactions with others. Tellingly, because of the struggles these conditions entail, our informants are more inclined to choose to stay at home.

5.4. Financial Aspects

Costs related to these conditions are increased by unsuccessful purchases, extra wear and tear, additional laundering and costs related to specialty and/or more expensive products. Indeed, we have already mentioned a number of aspects with financial implications for the informants and others with the same conditions, or as one of our informants with ostomy expressed it: "I do not have any problems with the quality of laundering result, the problem is the money". At the same time, laundry is one of the many extra costs in his one-man household: "there can be well over 10 washes per week, closer to 15".

Both of the diagnoses provide many more additional costs than those we describe; these include the cost of medicine, doctor visits, and expenses related to the adaptation of housing and transport. The overall economic situation affects their ability to buy clothing, as our retired stoma informant explained:

> With the minimum pension and the support of 600 Norwegian kroner[3], it is not enough to be able to build up a storage of bed linen or what it may be [that] you need. So it's always this struggle to have clean clothes.

Treatment costs must be prioritised: "Well, you have no choice but to purchase that service or product, and there will be less to eat. That's what's going on all the time; you have to prioritize everything that's about everyday living". His opinion on the expenses is clear: "It's expensive to be sick; that's the conclusion". Clothing is easily less prioritised because the treatment itself is more important. At the same time, a large supply of suitable clothes can contribute to making everyday life easier and reducing the burden of the disease.

6. Discussion

We initially asked what kinds of strategies people with these disabilities use to find clothes that fit and enable them to fit in. We will first discuss the three complicating aspects—the body, the market and the economy—before discussing the strategies our informants use to overcome these issues.

For our informants, the diseases make it harder for them to have control over their bodily secretions such as blood, dandruff, excreta, etc. Theories concerning dirt (Douglas, 1984) and the body (Mauss, 1979), as well as previous research, have shown that bodily secretions are subject to taboo and that the function of the clothes is to hide not only the body but also its secretions and its smell (Entwistle, 2000; Klepp, 2005). The secretions themselves, but especially not being able to control them, can easily become a stigma (Goffman, 1986), which is demanding for our informants. The conditions thus provide challenges in everyday life, which are about living not only with the effects of the disease, but also with the social side effects of the disease. They spend a lot of time, consideration, money and work to keep themselves and their clothes free of bodily secretions to 'pass', as Goffmann frames it, as a non-disabled person without any stigma (Goffman, 1986, p. 73).

Earlier research has shown that people with bodily deviations wear clothes both to hide the deviation but also to display it—to show that they accept themselves (Klepp & Rysst, 2017). Our informants, however, use clothes only to conceal the signs of the condition—for example, hiding the stoma bag with a long jacket or hiding the skin rash with long-sleeved and high-necked clothes. The most important way that the clothes are used to conceal the disability is through hard and frequent laundering. Our informants want to hide their lack of control over their bodily secretions and the malodour, and there is no indication that the informants would even consider choosing an opposite strategy. The possibility to keep the clothes clean is more important than the other requirements for clothing.

Clothes are also used to make the body look beautiful and make us look attractive and sexy. These aspects of the body and clothing were given low priority. We do not have enough material to discuss these aspects of the clothes in detail. However, we have some examples that the aesthetic aspects are prioritised by our informants in certain contexts, such as at work and parties. The aesthetic aspects are given especially little priority at home and at night. The fact that our informants can wear simpler clothing at home makes staying at home so much easier.

The diseases set requirements for clothing. They should not chafe already sensitive skin, nor should they squeeze the ostomy pouch while holding it in place. Both the diseases and their medication contribute to the bodies deviating from the ideal body and to the body size and

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[3] Equivalent to about 63 EUR or 74 US dollars as of September 2018.

shape potentially changing frequently. Therefore, finding clothes and shoes that fit is more difficult, and in addition, they need to be replaced more often. At the same time, they have reduced possibilities to try on clothes, and the result is often mistake purchases.

The clothing market is characterized by a lack of information but, even more alarmingly, also by faulty information about sizes and materials (Hardin, Wilson, Dhandapani, & Dhende, 2009; Laitala, Hauge, & Klepp, 2012). This makes it harder to find clothes that fit. On the one hand, several informants had personal experiences with materials that were suitable, but on the other hand, the labelling of viscose as bamboo was confusing. Viscose is a soft material, but it is also weak when wet; thus, it is easily damaged in laundering. Many of our informants knew this, but they did not now that bamboo is viscose. Thus, they acquired clothing in material that does not tolerate the harsh laundering they rely on.

We have so far presented our informant's stories about their own practices and reasons for them. We also tried to ask their thoughts about how clothes could help make their illnesses and lives easier. They had not really thought about it, which is completely in line with previous literature. There is little research on how clothing and textile materials can contribute positively, although some studies can be found, such as merino wool can be used to treat skin problems (Su et al., 2017) or that some clothes with different materials smell very different after reacting with sweat (Klepp, Buck, Laitala, & Kjeldsberg, 2016; McQueen, Laing, Delahunty, Brooks, & Niven, 2008). A more proactive attitude towards clothing consumption requires more knowledge, improved private economy and a better market.

The diseases also contributed to lower incomes for those who could not work or who could only work part time; the diseases also increased expenses for treatment and in daily life. Increased washing frequency, a larger number of mistake purchases and more damaged clothes are all factors contributing to increased clothing costs. A poorer economic situation leads to clothing having a lower priority, which, in turn, contributes to extra work and/or a reduced comfort level.

The different strategies the informants use to live with these challenges can be divided into three different categories. The first strategies are linked to the relationship between the clothes and the body. Clothes are used to conceal the disability; at other times, they are used to minimize the practical consequences of the illnesses. In everyday life, simple clothes are used that can tolerate hard and frequent washing. Nicer clothes were rarely used, and time and effort were invested in order not to damage them. The informants were less concerned with how the clothes could work positively to help ease the illness and improve everyday life; they were more concerned about how the clothes would not make things worse.

The second strategies are related to the connection between the clothes they wanted and the market; they are about how to access usable clothes and other textiles. They used mainly the mass market products, but not in a standardized manner. They opted out for special products for economic reasons and because they wanted to be as ordinary as possible, which is in line with earlier studies (Klepp & Rysst, 2017; Lamb, 2001; Thorén, 1996). Some customization took place by using clothes that were intended for other consumer groups—e.g., women using men's trousers or using maternity clothing while not pregnant. These strategies did not include so much sewing, but rather cutting off labels, rubber bands and other things that caused irritation. Many had not found a good solution for the problem of not being able to try on clothes, other than taking the burden of mistake purchases themselves.

The last strategy has to do with economics. They had different ways of reducing expenses, such as wearing old clothes when the disease was bad and buying the cheapest possible clothes from the regular clothing stores, even when these were not optimal. In summary, we can say that their main strategy was to reduce the requirements for their own appearance, but not to the body odours. If they were unable to appear decent, as at least odourless and stain free, they reduced their participation in social life, such as in work, or in leisure and physical activities. Not participating in such social activities is a strategy with major consequences for social inclusion, as it can potentially lead to social exclusion.

7. Conclusions

The ostomy and various chronic skin conditions have had a great effect on the everyday lives of our informants. They affect many aspects of clothing consumption, such as how purchases take place, which clothes fit, how much clothing they need, and in what way and how often they are washed. The conditions also make them avoid situations where they cannot be appropriately dressed.

Consumers with disabilities face various problems as clothing consumers, since they must search for clothing that meets their social, practical and technical requirements for functionality, comfort and aesthetics. The strategies are linked to the relationship between the clothes and the body. In some situations, clothes are used to conceal the disability, and at other times, they are used to minimize the disability's practical consequences. Other strategies are related to the connection between the clothes and the market; they are about how to get customized clothes and other textiles, such as bedding. The last strategy has to do with economics, as many people with disabilities have reduced income and have to try to get additional expenses covered by existing support schemes.

There is room for variation within the dress code, which would make it possible to adapt clothing despite the challenges that the body, the economy and the market set. This applies mainly to how the clothes look like.

There is much less acceptance for malodours and stains. The relationship between cleanliness and dignity is central for not only well-being, but also social inclusion, but this is little discussed in clothing research.

There is generally little knowledge about clothes in everyday life for people with different bodies, socioeconomic levels and physical and mental challenges. This study addressed only few informants and conditions, and the results given are, thus, just a starting point for future research on disabilities and clothing consumption. Further research should look at other diagnoses and conditions, and focus on women, men and children separately. We also believe there is an unexplored field at the intersection between medical research and clothing research. Textiles have different properties in terms of humidity, temperature regulation and resistance to odours; they could, therefore, be used more actively in treating these skin conditions as well as giving people with different bodies a worthy and comfortable life. To achieve this, we need to gain knowledge across disciplines and about physical and mental aspects of living. Clothing, appearance and cleanliness are important for everyone for practical reasons, but also for self-esteem, self-respect and participation in society. Studies of clothing can thus contribute to discussions about health and quality of life.

Acknowledgements

We would like to thank the patient organizations for all the help during research, and our informants for sharing their experiences so openly with us. We are also grateful to the anonymous peer-reviewers whose comments improved this article significantly.

Conflict of Interests

The authors declare no conflict of interest.

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Social Inclusion (ISSN: 2183–2803)
2019, Volume 7, Issue 1, Pages 136–151
DOI: 10.17645/si.v7i1.1597

Article

User Involvement of People with Mild Disabilities in Technology Innovations: Does It Make a Difference?

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Submitted: 5 June 2018 | Accepted: 4 September 2018 | Published: 31 January 2019

Abstract

In this study, we explored the role of people with mild forms of visual, hearing, physical, and cognitive impairments in innovation processes. Our research questions are: do the product evaluations by people with mild disabilities differ from those given by people without reported disabilities? If so, how? The analysis is based on eight focus group interviews conducted in Norway in 2016, in which 60 participants were asked to evaluate 11 energy-efficient product ideas. Four of the focus groups (two of men and two of women) were recruited based on the criteria of being mildly disabled. The remaining groups (two of men and two of women) had no such clause. The research results are ambiguous, indicating that the evaluations of new innovation by mildly disabled people correspond with those made by people without reported disabilities in some aspects and differ in others. However, the small size of the sample studied in this article suggests that the research results must be regarded as preliminary. Overall, the study reveals some interesting observations to be confirmed and disconfirmed in further research.

Keywords

disability; energy products; focus group; innovations; product-evaluation

Issue

This article is part of the issue “People with Disabilities: The Overlooked Consumers”, edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

1. Introduction

To contribute to a more sustainable society is a top priority in most European countries. To reduce the level of consumption, politicians can use several strategies. They can, for example, encourage consumers to reduce the level of consumption of products they already possess; to reorganize their consumer practices, for example, change from individually-based products to more collective (sharing-based) solutions; or to replace the products in use with more energy-efficient alternatives (Vittersø, Borch, Laitala, & Strandbakken, 2015). So far, the third strategy seems to be preferred because it, in contrast to the first, is expected to both benefit the environment and stimulate the economy. As a result, a number of new technologies have been developed and launched in consumer markets.

The competition in consumer markets is, however, high, and to succeed, consumers are increasingly involved in innovation processes. As most of these processes involve early adopters or other consumer groups tending to be more technologically skilled than the general population, it has been argued that some of these innovations will fail because they require a higher level of technological skills than the general population possesses, and therefore are too difficult to obtain and use. Moreover, in order to lower the level of skills, it has been suggested to involve people with disabilities in innovation processes (Migliaccio, 2016, 2017; Noonan, 1997/2007). A basic assumption is that the involvement of disabled people in innovation processes will benefit not only disabled people but also the general population. In a study of young disabled people's use of mobile phones, Mi, Cavuoto, Benson, Smith-Jackson and Nussbaum (2014) found that the informants preferred bigger screens and more tactile technologies rather than touch screens. Most likely, these are results that people without disabilities can also relate to.

Even though the argument for involving people in innovation processes seems intriguing, it has, to our best knowledge, not been empirically explored. To date, studies addressing the role of disabled people in innovation processes have focused on innovations of assisting technologies and educational programs (see, for example, Bühler, 1996; Chiu, Liu, Hsie, & Li, 2010; Joss, Cooclin, & Oldenburg, 2016; Ward, Raphael, Clark, & Raphael, 2016), whereas little attention has been paid to innovations of products targeting commercial, mass markets. To contribute to the ongoing knowledge development on user-involvement in innovation processes, we will in this article explore the potential role of people with disabilities in the innovation of energy-efficient technologies directed towards mass markets. Our research questions are: does the product-evaluation carried out by disabled consumers differ from that of people without disabilities? If so, how? We start with two theoretical sections outlining previous research on user-involvement in innovation processes and explain why a study of the potential role of disabled people in this process is important. After a description of the methodology, we analyze the research questions and discuss the research results' contribution to previous research on user-involvement. In the last, concluding section, we present research gaps for further studies.

2. User Involvement in Innovation Processes

Creating a more sustainable society has been on the political agenda in most Western countries for decades. To achieve this goal, new technologies are constantly being developed and launched in consumer markets (Jacobsson, Bergek, & Sandén, 2017). Critical to these technologies' success is the adoption of consumers (Noppers, Keizer, Bolderdijk, & Steg, 2014). A successful adoption means, in short, that all phases in the innovation process are completed: (1) the acquisition of knowledge about the innovation, (2) forming an opinion about it, (3) deciding whether to accept or reject the idea, (4) the implementation of the decision, and (5) continuing the use of the product (Kowalska-Pyzalska, 2018). A significant part of all products that are developed and launched in consumer markets fail to complete this process, not necessarily because the consumers dislike the technologies, but because they have not heard about the products or do not know where to get them or how to use them. The market failures cause massive losses—for businesses that have invested in the technologies, for authorities who have supported the innovations, and for consumers who missed a chance to get a better product.

To reduce the risks of market failure, consumers have been increasingly involved in research and innovation processes over the last decades. The user involvement of consumers has been theorized and discussed in several studies (Bianchi, Benedetto, Franò, & Frattini, 2017). Some of these studies are anchored in the seminar work of von Hippel (1994, 1998, 2005), and highlight the crucial role of users in innovation, and describe the innovation process in terms of distinct knowledge domains that producers and users possess. Producers possess knowledge about technical solutions, and users possess knowledge about their needs, the context of use, and their own capabilities as users. Both the knowledge of producers and the knowledge of consumers are characterized by "stickiness", that is, highly contextual and tacit knowledge that is difficult to transfer from one domain into another (von Hippel, 2005). Although designers and other actors representing the producers' side have certain representations of users in mind when they develop technologies, they usually fail to anticipate the practice of usage that eventually develops when the technologies are integrated into daily life (Akrich, 1995). Moreover, when technologies are in use, they are often misused or used in another way than anticipated (Rohracher, 2003, 2005). A frequently proposed solution to these problems is to intensify the interaction between producers and consumers. This can include producer participation in the consumer context, consumer participation in production, or consumer innovation (Heiskanen & Lovio, 2010).

Consumers involved in innovations processes are often "early adopters" (Droge, Stanko, & Pollitte, 2010). According to Rogers's (2003) theory, "early adopters" refers to the critical first market for the development and diffusion of new technologies. A basic assumption is that innovations tend to follow a bandwagon effect, where early adopters put pressure on later potential adopters to complete the adoption process. Hence, if early adopters accept or reject a technology, the technology will, respectively, succeed or fail. On the one hand, there are examples of innovations confirming this theory, such as the Sony Walkman, which became a success after being accepted by early adopters, and Google's Wave networking service, which became a failure after being largely rejected by early adopters (Bianchi et al., 2017). On the other hand, there are also examples of technologies that have failed despite being accepted by early adopters. Rather than grounding his theory on the bandwagon theory, Moore (1991) therefore suggests that early adopters have little or no influence on decisions made by later adopters.

As new technologies may fail to be transferred to other user groups, it has been argued that non-users are just as crucial, if not more so, in order to understand why some technologies fail to be successfully adopted. Non-use is not merely the delayed uptake or the massive absence of use, but rather a choice with many dimensions and motivations. In a recent study of non-use of smart energy services in Finland, Kahma and Matschoss (2017) describe six types of non-use: (1) lagging adoption (temporary non-use), (2) active resistance (a steadfast non-use due to a number of reasons, for example lack of privacy, time, other technology preferences or moral conditions), (3) disenchantment (reluctant use often due to nostalgic feelings), (4) disenfranchisement (non-use due to a lack of physical or cognitive skills), (5) displacement (non-use due to an outsourcing of use often to other family members), and (6) disinterest (non-use due to lack of interest in new technology). The authors conclude that disinterest, disenchantment, and lagging adoption are the most common forms of non-use. However, disenfranchisement also plays a role when innovations are rejected.

3. Why Study the Potential Role of People with Disabilities?

As disenfranchisement is seldom addressed in studies of innovation targeting mass markets, in this article we will study consumer groups with visual, hearing, physical, or cognitive impairments. With one exception, the consumers are mildly disabled, meaning that they face some extra challenges in everyday life due to their disability, but not to the extent that they need extra assistance, except from special equipment like glasses and hearing-aids (for a more detailed description of disability see Table 2). Moreover, we will concentrate on consumers who are in stage 1–3 of the innovation process, in which the consumers form their opinions about products and decide whether to continue the process. The product evaluations of disabled people will be compared to the product evaluations of people without reported disabilities. If they tend to make similar evaluations, their evaluations can be seen as representative of the general population; however, the argument for including them is weakened. If their evaluations tend to differ, they can be regarded as a consumer group with special evaluations; the argument for involving them is strengthened.

At this point, some specifications of the reasoning above need to be made. Firstly, all innovations do not necessarily require a higher level of skills than most people and, especially, early adopters possess. There are many examples of technologies that are easily used by most people, such as the earlier versions of televisions, which only have one button for “on” and “off”. As such, there are two parallel narratives of the technological development going on: one, in which technology makes consumers’ everyday lives easier, and another suggesting that it makes it all more complicated. In this research, we do not take a stand towards these narratives, but rather acknowledge that some technologies make everyday life easier, whereas others do not. Our concern is if, and to what extent, people with disabilities tend to use the products’ required level of skills as an argument for and against adoption more frequently than abled consumers. If they do, it makes sense to involve them in innovation processes. If they do not, an important argument for including them weakens.

Secondly, and more importantly, people with disabilities are not necessarily lower-skilled technologically than the rest of the population. Rather, we find it reasonable to believe that some disabled people are as technologically skilled as able-bodied people, if not more so, because they use technologies to compensate for their disabilities. This assumption is, to some extent, supported by research conducted by Mi et al. (2014), showing that disabled young people use technologies in the same way as able young people (for example, playing music, listening to audiobooks, and using the calendar). Hence, what we are addressing here are not necessarily people with reduced technological skills, but with disabilities that may or may not have reduced technological skills. Again, the crux of the matters is whether they tend to use their disabilities as an argument for or against adoption. If they do, it makes sense to involve them in innovation processes. If they do not, an important reason for including them is lost.

Involving people with disabilities in innovation processes because they are assumed to reduce the level of required skills of new technologies to the level that most people possess is, however, not the only reason why we find these consumer groups particularly interesting. Other reasons are as follows:

1. Having some extra challenges related to mild forms of disability is a “normal” condition which many people deal with, either permanently or temporarily. There are no statistics available showing the exact percentage of people with mild disabilities. We know, however, that approximately 11% of the population in Europe is disabled (Thomson, 2016). The degree of disability, or whether the disability is permanent or temporary, is, however, not clearly stated. Most likely, people with mild or temporary forms of disabilities are not included. The percentage of disabled people will most likely increase in the years to come mainly due to an aging population (European Commission, 2015). People with disabilities, therefore, constitute a significant part of the population and should be taken into account in innovations targeting mass markets.
2. In contrast to other types of barriers consumers face in everyday life, disabilities are not a matter of choice, but a reality with which people have to cope in everyday life. The question is, therefore, not how consumers can adjust to new technologies, but rather how the technologies can be adjusted to the consumers. If people’s hearing, visual, physical, and cognitive challenges are not taken into account in innovation processes, the technologies will most likely fail, simply because significant parts of the population cannot obtain or use them.
3. Despite representing a significant part of the population, little is known about disabled people as consumers (Borch, Kjørstad, & Slettemeås, 2017; Borch, Slettemeås, & Kjørstad, 2016a;

Borch, Kjørstad & Slettemeås, 2016b). Instead, researchers have created and institutionalized an "ablest" approach to consumer behavior, resulting in an idealized view of consumer reality since it overlooks various types of "consumer disadvantages" (Baker, 2006; Baker, Gentry, & Rittenburg, 2005; Kaufman-Scarborough, 2015; Piacentini, Hibbert, & Hogg, 2013; Woodliffe, 2007). Consequently, the voices of people with disabilities are seldom heard in product innovations. Markets are, in principle, open systems that should be accessible for all people (Slater & Tonkiss, 2001). Hindering people from taking part in markets threatens fundamental needs, such as belongingness, self-esteem, control, and meaningful existence (Kaufman-Scarborough, 2015), and has been regarded as a violation of discrimination laws (Borch et al., 2016a). In essence, increasing disabled people's access to markets is about the right to be a full member of society.

4. Involving disabled people in innovation processes may be beneficial for businesses. Based on a literature review, Migliaccio (2017) concludes that diversity and disability management can contribute to the creation of a stimulating, motivating, and empowering working environment, and thereby maximize the overall performance of companies. Diversity and disability management can also boost tolerance with positive effects in terms of reputation and thereby increase companies' overall productivity. Migliaccio (2017) also concludes that the beneficial impact on the economic system is often overlooked and that disabled stakeholders who are customers or users represent a substantial and growing target for companies that produce specific goods and services and are tailoring their strategies according to demand.
5. Research indicates that people with moderate or severe disabilities have stronger needs for some consumer goods and services than people without disabilities. For example, people with physical impairments tend to have higher energy consumption than people without such disabilities because they spend more time at home and need higher indoor temperature due to their reduced mobility (Stewart & Habgood, 2008). If properly designed, information and communication technologies (ICTs) can make the lives of disabled people easier, allowing them better interaction in society by widening their scope of activity, for example in education and employment (Migliaccio, 2016). Stronger needs for commercial products may be especially challenging for people with disabilities as they more often have low income due to a higher risk of being unemployed, working part-time, or being in low-paid work (Snell, Bevan, & Thomson, 2014). In addition, products offered to segments with special needs may be more expensive than products offered to mass markets as they are more costly to produce (Migliaccio, 2017). The unfortunate combination of increased needs, reduced income, and higher prices may make disabled people a highly engaged consumer group with a special interest of being involved in innovation processes.

In this article, we explore the user-involvement of mildly disabled people in innovation processes based on their evaluations of product ideas combining two presumably high-involvement products for disabled people: energy and ICTs. The project on which the analysis is based will be described in the following section which addresses methodologies.

4. Methodologies

The research is part of the EU-funded project NATCONSUMERS, conducted from 2015 to 2017 involving ten partners from different European countries. The project aimed to facilitate the development of a "natural language". The natural language could be anything—a dimming light, a sudden sound, a text—triggering consumers to reduce their energy consumption at home.

In this article, the natural language is given in the form of product ideas developed by 15 young designers (20 to 30 years old) in a workshop conducted in London in September 2016. All ideas involved energy-efficient technologies, although in varying degrees. The designers were asked to develop products encouraging different kinds of consumer segments to change their behavior based on the consumers' gender, age, interests, etc. About 15 project partners and five to six representatives from the project's stakeholder group were available for the designers if they needed assistance in energy-related questions. About 20 ideas were developed.

At the end of the workshop, the designers, the project partners, and some of the project's invited stakeholders evaluated the ideas and gave their votes to the best ideas: 11 ideas stood out as better than the others. Table 1 provides an overview of the ideas.

In January 2017, the 11 ideas were evaluated by four focus groups. The focus groups were all recruited by a recruiting company and varying by gender and household income (over and under NOK 700' per year). A rough analysis of the data material showed, however, minor or no differences between men and women and households with high and low income. We, therefore, decided to arrange a second round of focus groups, this time including people with mild disabilities. In all, four focus groups of disabled people were conducted in June 2017, two of which composed by women and the remaining two by men. The recruiting procedure was the same as the previous time with one exception: In contrast to the first round of focus groups, the second round only included people who responded positively on the question: do you have any forms of disabilities, i.e., visual

Table 1. The 11 product ideas evaluated. Source: Bent, Dromacque, Kmetty, Grigorou and Mikkelsen (2017).

Product ideas	Description of products
Individual technologies	*Technologies tending to be directed towards individual consumers*
Doctor appliance (Dr. App)	Dr. App is an app that allows you to have a full scan of the state of your appliances. It provides you with suggestions for improving the life of your appliances, detects if there are any irregularities, gives you a recommendation on your usage and when it is time to buy another one, shows you other appliances on the market with a detailed analysis and all possible incentives and discounts available.
Interactive Energy Story Platform	The Interactive Energy Story platform provides its users with unique stories based on the energy consumption of the household through a code on their bill. Users receive a new chapter of these short novels every month. In the background, issues concerning ecology, sustainability, responsible consumption, etc. help to raise awareness about energy savings and green living.
Feeding Your Appliances	The app simplifies household energy management: the kWh are translated into units like "energy Lego bricks". You can allocate your energy units to each of your appliances or reorganize your units according to advice on energy saving. Understanding energy management through reallocating units between your household appliances is very simple. Saved units can be stored for upcoming months or given to charities.
I challenge you	An app that provides you with interactive visualization of your energy consumption by being connected to your smart meter. It is an intuitive and visual interpretation of data that makes it possible for you to surf through the data in different ways. It also informs you how to work better on your energy consumption. There is the possibility of adding your friends and family to see how your community is working on their energy consumption.
Family technologies	*Technologies tending to be directed towards households*
Energy Frame	Energy Frame is a visual representation of your energy consumption through a tree—the more you save, the more the tree evolves and flourishes. People can join others and create a forest of trees and get tips and advice on how to reduce consumption. It can go from a decorative and contemplative image to a more interactive game.
ThunderFly	The ThunderFly is a little object which reflects energy consumption through visual information. The ThunderFly glows, showing the on-going consumption of the household. When it glows more vividly it means consumption is getting higher and you should verify what is going on through the app of your mobile. The ThunderFly is a gentle reminder of family energy consumption. Every month the ThunderFly delivers the family energy report.
Cooperative technologies	*Technologies tending to be directed towards cooperatives*
Energy Saving Platform	The Energy Saving Community Platform is a digital platform where groups of consumers can team up to save money by reducing their household energy consumption. The money saved goes into a common fund to be used for community projects. Community meetings and workshops allow members to define projects they wish to create and to learn about consumption and to share tips and tricks on energy saving.
E-Pooling	E-Pooling is a social platform targeting single households, people seeking company and older individuals to engage in shared interests and activities. By socializing, users reduce their energy consumption. Indeed, they gather in one place and use only the appliances of that space for collective purposes.
Children's technologies	*Technologies tending to be directed towards children*
Energyland	An educational system of challenges for children that aims to teach them and raise their awareness on energy saving and careful energy consumption. There are different challenges children can unlock by practicing careful energy consumption at home. The system is managed by teachers who send challenges to kids and give them physical badges that can be shown in class and help stimulate the competition among children and schools.

Table 1. (Cont.) The 11 product ideas evaluated. Source: Bent, Dromacque, Kmetty, Grigorou and Mikkelsen (2017).

Product ideas	Description of products
Children's technologies	*Technologies tending to be directed towards children*
Housemonsters	Housemonster is an augmented reality app which allows end-users to save energy by engaging with their 'house monster', which represents energy incongruences of the devices. Parents and kids will have family monster assistance which will send push notifications when some actions can be taken in order to save energy.
Piggy bank	A piggy bank is an app showing children how much money they save by changing their family energy consumption habits. It makes energy saving simple and engaging for kids because it makes it tangible. By making immediate changes such as switching off the lights, their piggy bank shows them how much they're saving. The saved energy makes the difference in kids' pocket money and engages them in saving more.

or hearing impairments, or physical or cognitive disabilities? Notably, we do not know if the participants of the first groups have some kind of disability. As some of them might be disabled, the difference between the "disabled" and the "able" are probably more diffuse than it could have been if the participants recruited in the first round had answered negatively in the same question.

Participants were given a free meal (pizza and lemonade) and NOK 500' in gift certificates. The sample may, therefore, be slightly biased in terms of including people that are either interested in residential energy consumption, or like the idea of getting a free meal and some extra income. The focus groups included 5 to 10 participants. Table 2 provides an overview of the focus group participants included in the analysis's sample.

As shown in Table 1, most participants were between 40 and 60 years old, highly educated (12+ years of education) and work full time (cf. Snell et al., 2014). The number of participants not working full time is higher in the focus groups with disabled people, especially in one of the focus groups composed by men with disabilities (MD1). The only participant who was severely disabled was a member of group MD1. Although this group stood out as more critical than the others (see Table 3), the man was not more critical than the most talkative members of the group. Most likely, his severe impairment did not affect the group discussion.

The aims of the focus groups were: (1) to examine participants' evaluation of the product ideas' presumed product qualities and their chance of being purchased and used by themselves or their families, and, hence, (2) to identify the product ideas with the highest potential to reduce residential energy consumption. The main questions were: do the participants report that the products would be purchased and used by them or their family in short and longer terms? Why? The focus group design followed seven main steps:

1. The moderators introduce the project and the participants introduce themselves;
2. The participants talk about the residential energy consumption of their households;
3. The moderators present the product ideas visually and orally by showing a PowerPoint presentation and describing the content;
4. The participants get a handout of the product ideas and study the ideas individually with assistance, if needed, from the moderators;
5. The participants discuss the product ideas together, one by one, and agree on whether they are basically positive, negative or both positive and negative;
6. The focus groups close.

Each focus group took two hours and took place at SIFO. All groups were moderated by the researchers. When the product ideas were presented, the participants were instructed to ignore the fact that some of the product ideas were based on technologies that had not been developed or were unknown to the focus group participants. Rather, they should talk as if all the technologies were available. The moderators made sure that all participants understood all of the tasks and questions and had a chance to make their voices heard.

The analysis was conducted in three main steps. First, we categorized the eleven product ideas. As shown in Table 1, we divided the ideas into four categories: individual-oriented technologies, family-oriented technologies, cooperative technologies and children's technologies.

In the next step, we mapped the positive, negative, or ambivalent opinions about the product ideas that the participants had agreed upon during the focus group. In Table 3, positive and negative evaluations are given 2 and 0 points, respectively. Product ideas, for which no agreements were reached were regarded as neither positive nor negative and given 1 point.

Finally, we registered all arguments for and against each idea and divided them into nine categories: cultural/practical, educational, technological, social, emotional, esthetical, environmental, economic, health, and moral (see Table 4). We also made a table showing the number of times each argument had been voiced. However, as this table is too encompassing to be shown

Table 2. The four samples by disability, income, age, education, and position.

	Disability/income	Age	Education	Position
Women, disabled 1 (WD1)	Physical	28	High	Full time
	Physical	46	High	Unemployed
	Physical	52	High	Disabled
	Visual	33	High	Full time
	Visual	28	High	Full time
	Hearing	45	High	Full time
	Cognitive	59	High	Full time
Women, disabled 2 (WD2)	Physical	52	High	Disabled
	Physical	61	Middle	Disabled
	Physical	65	High	Pensioner
	Visual	60	High	Full time
	Cognitive	29	High	Full time
	Cognitive	23	Middle	Full time
	Cognitive	29	High	Full time
Men, disabled 1 (MD1)	Physical	57	High	Disabled
	Hearing	35	High	Full time
	Visual	65	High	Pensioner
	Cognitive	43	Low	Disabled
	Hearing	63	High	Full time
	Visual	46	High	Full time
	Physical	50	Middle	Full time
	Cognitive	41	Middle	Full time
Men, disabled 2 (DM2)	Physical	57	High	Full time
	Visual/hearing	39	Middle	Disabled
	Physical	65	Middle	Pensioner
	Physical/Hearing	56	Low	Disabled
	Physical/visual	49	Middle	Disabled
	Visual	52	Low	Unemployed
	Cognitive	35	High	Part-time
	Hearing	63	High	Full time
	Physical/hearing	44	High	Disabled
	Cognitive	53	High	Part-time
Women, low income (WLI)	NOK 200’/399’	29	High	Full time
	NOK 400’/499’	34	High	Full time
	NOK 400’/499’	49	High	Full time
	NOK 200’/399’	46	High	Part-time
	NOK 500’/599’	57	High	Full time
	NOK 400’/499’	41	High	Full time
	NOK 400’/499’	54	High	Full time
	NOK 400’/499’	61	Middle	Part-time
Women, high income (WHI)	NOK 1,2 mill	52		Full time
	NOK 800’	42	High	Full time
	NOK 1,1 mill	51		Full time
	NOK 1,1 mill	43		Full time
	NOK 990’	38	High	Full time
Men, low income (MLI)	NOK 400’/499’	46	High	Full time
	NOK 500’/599’	45	High	Full time
	NOK 500’/599’	49	High	Full time
	NOK 500’/599’	50	High	Full time
	NOK 600’/999’	53	Middle	Full time
	NOK 600’/999’	35	High	Full time
	NOK 500’/599’	63	Middle	Part-time

Table 2. (Cont.)The four samples by disability, income, age, education, and position.

	Disability/income	**Age**	**Education**	**Position**
Men, high income (MHI)	NOK 1 mill	38		Full time
	NOK 1,3 mill	50		Full time
	NOK 1,2 mill	49	High	Full time
	NOK 1,1 mill	47	High	Full time
	NOK 1,1 mill	58	High	Full time
	NOK 1,6 mill	52		Full time
	NOK 1 mill	52	High	Full time
	NOK 1,1 mill	44	High	Full time

within the scope of this paper, we made a brief version of it showing the number of times each category of arguments had been expressed (see Table 5). All in all, 242 arguments were identified. Note that Table 5 does not show how many times each argument within a category of arguments was mentioned, nor does it show the length and intensity of the different arguments. We believe, however, that the table, all in all, provides a valid overview of the different arguments used in the participants' evaluation of the product ideas.

5. Preferred Ideas

So far, we have described the theory and methodology on which this article is based. In this section, we present the main results of the analysis. Table 3 shows the focus groups' evaluation of the product ideas.

Table 3 indicates that people with mild disabilities tend to have lower preferences for individual-oriented energy-efficient technologies and higher preferences for cooperative oriented energy-efficient technologies. Why people with mild disabilities are more collectively oriented than others is hard to tell based on the information available. One hypothesis might be that there were more singles in the sample of people with disabilities, which may increase the preference for collective solutions. However, if more participants were single, we might expect that they would largely prefer individually oriented product ideas than people without mild disabilities, which is not the case.

Table 3 also indicates that men with disabilities tend to have lower preferences for new energy-efficient technologies. Interestingly, in one of the focus groups (MD1), none of the product ideas were positively evaluated. This group was not the group with the highest numbers of unemployed. As such, the result does not reflect that the members of this group are more likely to refuse products due to low-income.

Table 3. Participants' preferences related to new, energy-efficient technologies by disability, gender, and economic income.

Product ideas	**Participants' evaluations**									
	WD1	**WD2**	**MD1**	**MD2**	**Tot**	**WLI**	**WHI**	**MLI**	**MHI**	**Tot**
Individual technologies	6	0	1	2	**9**	2	4	5	4	**15**
Dr App	2	0	1	1	4	0	0	2	1	3 (7)
Interactive energy stories	0	0	0	0	0	0	0	0	1	1 (1)
Feeding your appliances	2	0	0	0	2	2	2	2	0	6 (8)
I challenge you	2	0	0	1	3	0	2	1	2	5 (8)
Family technologies	3	3	1	4	11	4	4	3	2	13
Energy frame	2	1	1	2	6	2	2	1	0	5 (11)
Thunderfly	1	2	0	2	5	2	2	2	2	8 (13)
Cooperative technologies	2	2	2	1	**7**	1	2	0	1	**4**
Energy saving platform	2	2	1	0	5	1	1	0	0	2 (7)
E-pooling	0	0	1	1	2	0	1	0	1	2 (4)
Children's technologies	4	4	0	6	14	2	6	4	4	16
Energyland	2	2	0	2	6	0	2	2	2	6 (12)
Housemonsters	1	0	0	2	3	2	2	0	0	4 (7)
Piggy bank	1	2	0	2	5	0	2	2	2	6 (11)
Total	15	9	4	13	41	9	16	12	11	48
Gender diff	24		**17**			25		23		

Note: 0 = negatively evaluated; 1 = negatively/positively evaluated; 2 = positively evaluated.

6. Arguments for and against Adoption

Although the preferences are the same, the reasons behind these preferences may differ. Table 4 provides an overview of the arguments "for" and "against" behind the participants' evaluations.

Table 4 shows that there were arguments both for and against adoption of different kinds: cultural/practical, educational, technical/conceptual, social, emotional, esthetical, environmental, economic, health, and moral/juridical. Overall, there were more negative than positive arguments for or against adoption, which underlines the importance of non-use studies (cf. Kahma & Matschoss, 2017). Table 5 shows the number of times each focus group mentioned one type of argument for and against adoption. As shown in Table 5, some of these arguments were more frequently voiced than others.

Table 5 indicates that arguments for or against adoption, to some extent, vary between people with and without reported disabilities. The table shows that peo-

Table 4. Arguments for and against adoption of product ideas.

	Arguments for (positive arguments)	Arguments against (negative arguments)
Cultural/ practical	— **Covers a need** — **Possible** to develop, cultural conditions considered	— **Covers no need/not beneficial enough** — **Already exist** — **Not practical use**. Does not work in practice/not part of our socialization — **Unrealistic**, cultural conditions considered
Educational	— Raises **awareness** — **Informative**, including pedagogical — **Visualizes** your **consumption** — Creates a sense of **achievement** — Enables users to **compete individually** (with themselves)	Demands too much **technical skills**
Technological or conceptual functionality (Te)	— **User-friendly** — **Universal Design** (for example, "Not too loud—to please people with hearing impairments") — **Smart** (technically innovative)	— **Self-effacing**. The product makes itself superfluous when used ("When you have used it, you no longer need it") — **Does not benefit users:** the one who saves money is not the same as the one who gets the benefits — **Target wrong users:** the target groups (for example, children) are not in charge of the household's energy consumption — **Wrong motive**. May save energy, but for other reasons — **Inexplicable**. Not clear how it works — May **involve data privacy** problems
Social (So)	— **Meet people** — **Fits all** people — **Fashionable** — Provides **social status** by making your energy consumption visible — Enables users to **compete socially** (with others) (N) — Creates **social pressure** by visualizing users consumption	— **Mayfly** (gets unfashionable quite soon) — Creates **social pressure** by visualizing users consumption — Creates **pillories** by visualizing users consumption — Reveals **social differences** by visualizing users consumption — Enables users to **compete socially** (with others) — Risk of **free-riders** — **Conflicting**
Emotional (Em)	— **Likes** it — **Fun** (for example, for kids) — **Nostalgic** ("It reminds me of the thermometers my grandparents and parents used to have in the 70s") — Nice to get a **reward**	— **Dislikes it** — **Not fun** (for example, boring over time) — **Annoying**/distracting
Esthetical (Es)	**Decorative**	Does **not fit** with the **interior** at home **Ugly design**

Table 4. (Cont.) Arguments for and against adoption of product ideas.

	Arguments for (positive arguments)	Arguments against (negative arguments)
Environmental (En)		— **Inefficient**, i.e. does not save enough energy in the household — Does not save enough energy in a product's **service life** — Vulnerable for **rebound effects**: The money/ extra money you got due to your energy saving is used on energy-demanding consumption
Economic (Ec)	**Save money**	— The product would most likely be too **expensive** — The product provides **pester power** — "**Commercial**". Information that might have been offered by a commercial sender
Health (He)		— **Deactivating**
Moral/juridical (Mo)	**Good cause**	— **Distracting**. Takes your attention away from more important things in life — **Wrong motive**. May save energy, but not for the environment, not to save money — **Materialism** ("this is just another thing…") — **Information panic** (too much information) — **Data privacy** (who gets the information)

ple with reported disabilities made more arguments for and against the adoption than people without disabilities (131 versus 111 arguments).

In both groups, emotional arguments are most frequently voiced, especially "likes it". The emotional arguments were more frequently used by people without disabilities (33 versus 21). Also, social and educational arguments were frequently voiced. Whereas social arguments were expressed equally by both groups, educational arguments were more frequently voiced by people with disabilities (29 versus 19).

Table 5 also indicates that people with reported disabilities seem to have more moral arguments against adoption (1 versus 10 arguments). The most frequent moral argument for adoption was "good cause", whereas the most frequent negative arguments were "distracting" (the idea takes attention away from more important things in life) and "wrong motive" (the proposed product may save energy, but for other reasons than concern for the environment). Typically, participants argued that Piggy bank taught children to save energy for economic rather than environmental reasons.

People with disabilities also voiced more technical arguments against adoption (12 versus 8) than able participants. Most frequently, the participants did not understand how the product worked.

In the analysis of preferred product ideas, men with disabilities stood out as more negative towards the new ideas than others. This tendency can also be observed in Table 5, where disabled men gave eight arguments for and 16 arguments against adoption.

Other results worth mentioning do not seem to be related to the participants' disability. One of them is that emotional arguments are more frequently expressed in the discussion about the most and the least popular preferred products idea, Thunderfly and Energy stories, respectively, than in discussions about other product ideas. The most frequent argument for adopting Thunderfly was "likes it". Interestingly, nostalgic feelings were mentioned six times as an argument for adopting this application. None of the other product ideas seemed to arouse such feelings.

Social and cultural/practical arguments are more frequently expressed regarding the cooperatively oriented product ideas (Energy-saving platform and E-pooling). Many participants valued the social aspect of these ideas but believed that Norwegians are not ready for sharing economy mainly due to an individualized culture.

The educational aspects of the product ideas were most frequently expressed in discussions about the individually oriented technologies (for example Feeding Your Appliances and I Challenge You) and children-oriented technologies (especially Energyland). Whereas the informative aspect was highlighted in the former, the upraising potential was highlighted in the latter.

Economic arguments were most frequently expressed in the discussion about Dr. App and Energyland, where the groups of women with disabilities and with low

Table 5. The frequency of the arguments for (P) and against (N) adoption of product ideas, by type of argument.

Product ideas	**Arguments**															
	WD1		**WD2**		**MD1**		**MD2**		**WLI**		**WHI**		**MLI**		**MHI**	
	P	N	P	N	P	N	P	N	P	N	P	N	P	N	P	N
Individual technologies																
Dr. App	Cu Ed Ed	Ec	Ed	Em Te Ec Ec En	Ed	Ec	Ed Em	Cu	Em Ed Cu	Te So Ec Ec		En	Em Cu Ed		Em Ed	En
Interactive Energy Stories		Te	Em	Em Te		Em Cu		Te		Em				Em Cu		Te
Feeding Your Appliances	Ed So Ed		Ed	Te Te		Cu Mo		Te	Ed Ed	Te	Ed	Em Ed Cu		Cu Te	Em	
I Challenge You	Ed So Ed Ed	So		Ed	Te Ed Ed	So Cu	Ed	Cu So Mo	So	So	Em So	Em		Cu	Em	Ec Mo
Family Technologies																
Energy Frame	En So Es Ed Ed	Cu	Em Ed So Em	En Te Es So	Em Em	Mo	Ed	Ec	Em Ed		Es So Em	Es		So En	Em Te	So
ThunderFly	Em So	Mo	Em	Es	Em	Te	Ed	Mo	Em Es Ed		Ed Em	Ed	Ed Em Em		Em Em	
Cooperative Technologies									Em							
Energy Saving Platform	Em Cu Ec So	Cu So Cu So	Cu Cu	Cu Te En	So	Te So So	So Mo	So	So	En Cu So Cu	So So	Cu Em Cu		Cu So So		So Te So
E-Pooling	So Mo So	Cu Ed En	So Em	Mo Ed		Cu	So	Te	So	Cu	So	En		Cu	So	
Children Technologies		Ed														
Energyland	Em Ed Ed		Em Ed Ed	En		Te	Ed So		Em Ed Ed Em So	Em So	Em So En	So	Em			
Housemonsters	Em	He Mo	Em	Ec Te		Mo	Em Ed Ed		Em Ed Cu Em		Em Ed	So Em	Em	Cu	Em	Te
Piggy Bank		Mo	Em			Mo	Em			En	Ed	Te	Em Em		Ed	

income emphasized the extra costs of replacing old technologies with new and more sustainable technologies:

> I think that if this [Dr. App] told us that this [apparatus] does not function anymore, it will put a pressure on households. I know that my refrigerator and freezer are not new, but I can't afford to buy a new one. Should I feel bad because of this? Nowadays, you are expected to change to more efficient applications to save the environment or reduce your energy bill, but we can't replace our refrigerator because we can't afford it. It all depends on where you are in life, your social premises, it is not 'only' about replacing things. (Women with disabilities)

A similar argument was made by a woman with low income, who worried that children living in poor households would be victims of the extra costs of adopting energy-efficient products:

> This [Energyland] shall be used in schools. It will be shown to everybody. Not all have the same financial premises, which implies that some will have better opportunities to save energy than others. It costs NOK 250' to replace a led lamp, so it can be quite expensive. Not all can afford this. Such things need to evolve gradually. Children [from low-income families] have to stand in front of their classmates and tell them that we can't afford to save energy. I don't like it. (Women with low income)

Only two women used disability as an argument for or against adoption. One of these comments addressed hearing impairment:

> Good for people with hearing impairments…if you can turn the sound up and down. I never turn the sound up too much since I have hearing problems. (Women with hearing impairment, in a discussion about Thunderfly)

The other comment using disability as an argument addressed cognitive and visual impairment:

> It is easy to understand for everybody. No difficult explanations. It is easier with pictures for those who think that text is difficult. (Women with physical impairments, in a discussion about Feeding Your Appliances)

Neither disabled women nor disabled men tended to use technical skills as an argument for or against adoption of the 11 products. The closest we got was a disabled woman who commented on the sharing economical idea, E-pooling, suggesting that old people would not dare use their neighbors' washing machines if they were allowed to, as they could not understand which button to push. The relevance of this argument was, however, demonstrated several times by both participants with and without disabilities. For example, the following conversation took place in phase 2 of the focus group of low-income men:

> Man 1: I am so unconscientious because we have these very nice ADAX furnaces at home which can reduce the indoor temperature at night if they are activated.
> Man 2: Same! We also have ADAX furnaces, which we haven't programmed the last two years.
> Man 1: Yes, I do not know how to program them.
> Man 2: Yes, it is difficult….If you make mistakes, you have to do it all again, plot in all the days, plus the time when the temperature should increase and decrease during the day.

Overall, we regard the dialog above as an illustrative example confirming previous research indicating that some technological innovations offered in consumer markets today require a higher level of technical skills than most people possess.

So far, we have presented the main results of the study. The next question is what these results add to previous studies of user involvement.

7. Discussion: The Study's Contribution to User-Involvement Studies

Most studies of user involvement focus on able consumers, or, although less frequently, people with moderate or severe disabilities. In this study, we have, however, addressed people with mild impairments. The study indicates that product evaluations made by mildly disabled people, to some extent, are similar to those made by people without reported disabilities, and in some respect differ. For example, both people with and without reported disparities liked Thunderfly best and Energy Stories least. Their corresponding product preferences were probably the result of shared culture-historical roots. Symptomatically, Thunderfly was the only product idea arousing nostalgic feelings in both groups, apparently because it reminded the participants about their childhood in the 1970s when their parents or grandparents had a meter hanging on the wall showing the household's energy consumption. When an arrow in this meter entered a red zone, the energy price increased. The production of the meter stopped when price differentiation during the day was abolished. Still, more than four decades later, a similar metering seems to create nostalgic feelings among consumers, disabled or not.

On the other hand, there are observations indicating that there are differences between people with, and without, mild forms of disabilities. One of the observations worth noticing is that people with disabilities tend to articulate more arguments for and against the adoption of new products than people without reported disabilities. This is in line with previous research indicating that people with disabilities represent a highly engaged consumer group due to an unfortunate combination of increased needs, reduced income, and higher prices for products for people with special needs (see section 3, point 5).

Another observation indicating differences is that technical arguments were more frequently voiced by people with disabilities, their main concern being that they did not understand how the product worked. This observation confirms the assumption on which this study is based, namely that user-involvement of people with disabilities in innovation processes may lower the level of required skills so that more people will find them easier to obtain and use. The basic assumption is also confirmed by the observation that the only focus group participant that used disability as an argument for or against adoption, was a disabled woman. That being said, the clearest statement articulating the need to lower required skills in new innovations was voiced in a focus group with people without disabilities. Hence, although more frequently voiced by people with disabilities, the need to lower technology skills was also acknowledged among the able consumers participating in this research.

Another observation indicating that the evaluations of people with mild forms of impairments differ from those made by people without disabilities is that moral arguments were more frequently expressed by people with disabilities, their most frequent arguments being that the product would take attention away from things that really matter in life. Interestingly, this argument was most frequently voiced by a group of men with disabilities that, in this research, stood out as more critical towards the examined product ideas than others. Involving critical consumer groups can both hinder the development of good product ideas as well as the development of unnecessary products. In a world of “economic growth”, in which priority is given to the third strategy (based on the paradoxical notion that the current level of CO2 emissions shall be reduced through increased production; cf. Vittersø et al., 2015), the importance of involving consumers hindering innovations of unnecessary products shall not be underestimated. Without such consumer groups, unnecessary products will be developed—diminishing our chance to achieve the political goal of creating a sustainable society.

An often-articulated criticism in studies of user-involvement is that user groups tend to get involved in the innovation process too late, often in a phase where the product is already made and, therefore, hard to change. In this study, we have brought consumers in at a very early phase, in which new ideas are developing and, therefore, are in the middle of a process or change. The study indicates that people with disabilities are more engaged in this phase than people without reported disabilities in the sense that they are articulating more arguments for or/and against adoption. This is in line with previous research indicating that energy-efficient technologies are a high-engaging product for many disabled consumers, which also speaks for involving them in innovation processes. That being said, this study has only addressed stage 1–3 of consumers’ adoption process (cf. Kowalska-Pyzalska, 2018). To what extent the consumers will complete the innovation process to stage 4–5, is therefore unknown and requires further studies.

Most studies of user-involvement have focused on developing a theoretical framework (see, for example, Etgar, 2008; Ojanen & Hallikas, 2009) and discussions regarding benefits, challenges and reasons for engaging users in innovation processes (Elofson & Robinson, 2007; Franke, von Hippel, & Schreier, 2006). Many studies have been based on case-study methodologies, where one innovation is typically approached from several angles. A criticism of case studies has been that consumers are only involved in one innovation, which reduces the possibility to see how they relate to other innovations. In this study, we have explored user-involvement in many innovation processes. In all, 11 product ideas have been evaluated by people with and without reported disabilities. The study indicates that one consumer’s evaluations can vary from one product to another. In some innovations, a consumer may appear as an “early adopter” accepting the product; in other innovations, she or he appears as a “non-user” rejecting it. The categorization of consumers as different types can, therefore, be difficult and should be used with caution.

Even though the evaluations of different products tend to vary, this research has indicated that some consumer groups tend to act similarly regarding more innovations. For example, men with mild disabilities seem to be more reluctant too new and efficient energy technologies than other consumer groups. The sample is, however, small, and to what extent this result can be generalized to other groups of disabled men needs to be explored in further studies.

So far, most studies of user-involvement in innovations targeting mass markets have focused on early adopters. This study has, however, brought new insight regarding non-users. Also, in this context, the observation made concerning disabled men stands out as particularly interesting. The group’s main argument for turning product ideas down was that new technologies take attention away from more important things in life. Why disabled men appear to be more prone to refuse new technologies for moral reasons is one of the questions which need to be further explored should this group of consumers be followed up in further studies.

Given the large part of the population with disabilities, disenfranchisement in the form of reduced skills is seldom used as an argument against the adoption of new technologies. The tendency not to use this argument is also observed in this study, showing that the only participant using disability as an argument was a disabled woman. The tendency not to use this disability as an argument does not indicate that lack of skills is an unimportant argument in innovation processes. More likely, it indicates that low skills are not an argument that tends to be used in settings like focus groups. If the interviews had taken place in another setting, for example individual, face-to-face interviews that to a larger extent allow more intimate, dualistic relationships between interviewer and interviewees, disabilities might have been used more actively as an argument for and against adoption.

Last, but not least, this study has demonstrated the relevance of connecting studies of adoption processes to studies of user-involvement. Whereas studies of user-involvement tend to focus on how different kinds of actors are involved in innovation processes, adoption studies focus on the how the innovation is received in consumer markets. As the main reason for including consumers in innovation processes is to increase the innovations' chance of success, the two fields of knowledge represent two sides of the same process. More effort should, therefore, be conducted to merge these fields of knowledge more systematically, emphasizing where the two sides complement each other and where new knowledge is needed to fill in research gaps.

8. Conclusion

In this study we have analyzed the role of disabled people in innovation processes based on a study exploring whether the evaluations of energy-efficient product ideas made by people with mild forms of visual, hearing, physical, and cognitive impairments differ from those given by people without reported disabilities.

The main conclusion of this article is that the research results are ambiguous. In some respect, the product evaluations of the two groups seem to be the same; in other respects, they seem different. Most importantly, the research indicates that people with disabilities seem to be more engaged in innovation processes than people without disabilities, probably due to experiences they have had by virtue of representing a group of "disadvantaged consumers" in an ablest consumer culture (Kaufman-Scarborough, 2015). It also indicates that disabled men are more likely to reject products they do not need than people without disabilities, and, hence, appear as a type of "non-use" consumers without which the political goal of creating a sustainable society will be difficult, if not impossible, to achieve. In addition, the research indicates that people with disabilities tend to use more technical arguments against adoption, their main argument being that they do not understand how the product works. This argument is, however, also voiced by people without disabilities, suggesting that this is a general problem that should be handled by means of universal solutions and design.

Overall, the research has increased our knowledge regarding the potential role of disabled people in innovation processes. That being said, the small sample explored suggests that the main conclusions of this study must be regarded as preliminary results to be confirmed or disconfirmed in future studies. Also, the conclusions cannot be generalized to other research settings, for example, research settings addressing moderately or severely disabled people (rather than mildly disabled people); innovations of food, clothes, or other products (rather than energy-efficient technologies); phase 4–5 of the innovation process (rather than phase 1–3); and innovations that will be launched in markets (rather than innovations that might be launched). Research shows that innovation processes often include researchers, businesses, and other stakeholders with different perspectives and that the relationship between the different stakeholders can be characterized by asymmetric information and power imbalances (Steel, Layton, Foster, & Bennett, 2014). Hitherto, little is known about how processes of user involvement unfold (Geer & Lei, 2012). Even less is known about how these processes unfold if they include people with disabilities.

Acknowledgments

Thanks to all who have contributed to this manuscript: The NATCONSUMERS consortium and the reviewers of this journal.

Conflict of Interests

The authors declare no conflict of interests.

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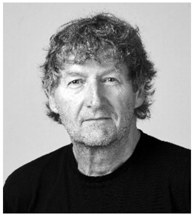

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COGITATIO

Social Inclusion (ISSN: 2183–2803)
2019, Volume 7, Issue 1, Pages 152–163
DOI: 10.17645/si.v7i1.1706

Article

The Drake Music Project Northern Ireland: Providing Access to Music Technology for Individuals with Unique Abilities

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Submitted: 30 July 2018 | Accepted: 24 October 2018 | Published: 31 January 2019

Abstract

Across the UK, a growing number of charity organisations, social enterprises, academic researchers and individuals have developed music technology-based music workshops and projects utilising Accessible Music Technology to address the issue of access to music-making for people with disabilities. In this article, I discuss my ethnographic study of The Drake Music Project Northern Ireland (DMNI), a charity which provides music workshop opportunities in inclusive ensembles at the community level. My methodology of participant observation involved undergoing the training necessary to become an access music tutor for DMNI, attending workshops and conducting interviews with people throughout the organisation. Key findings were that consumer music technology devices that were not designed to be accessible to a wide spectrum of users could be made accessible through adapting them with other devices or different sensor interfaces more suitable for people with unique abilities and specific needs. Throughout my study I found that it was not in the design of music technology devices that made them accessible. Rather, meaningful music-making emerged through the interrelations between the access music tutors, workshop participants and the music technology interfaces in the workshop environment. The broader implications of DMNI music-making activities and effects on social inclusion are also discussed.

Keywords

accessibility; design; digital; digital musical instruments; disability; music; music technology; social inclusion

Issue

This article is part of the issue "People with Disabilities: The Overlooked Consumers", edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

1. Introduction

Across the UK, a growing number of charity organisations, social enterprises, academic researchers and individuals have developed music technology-based music workshops and accessible devices to address the issue of access to music-making for people with disabilities. Examples of organisations that provide music-making opportunities with music technology exist in the form of community music and disability arts organisations operating at the community level. In this article, I discuss my ethnographic study of The Drake Music Project Northern Ireland (DMNI), a charity which works at the intersection of disability, music-making and music technology. DMNI states that it exists to provides access to independent music-making for children and adults with complex disabilities through the use of Accessible Music Technology (AMT). AMT practices entail matching or adapting a music technology device to a user's specific need.

Another field which has influenced this sphere of musical activity is Digital Musical Instrument (DMI) design and research into new interfaces for musical expression. Academic researchers and independent technologists interested in musical instrument design see the challenges of creating new DMIs as a form of creative expression in itself. In this area of DIY (hobbyist and alternative to consumer) technology making, highly customised adaptations and original designs are often customised and unique to the inventor. This high level of customisation is due to the versatility and variety of easily-available contemporary sensor interfaces that can be incorporated into instrument designs. These low-cost digital components have made it possible for makers to use their skills towards creating bespoke Accessible Digital Musical Instruments (ADMIs) customised to the unique requirements of an individual or group of users with disabilities.

In this article I discuss the use of consumer music technology, AMT and ADMIs in DMNI through my research questions: 1) To what extent does the design of devices exclude certain users from engaging with music technology? 2) In what ways can inclusive music-making with music technology contribute to the lives of participants with different abilities?

2. Inclusive Music Education

Musical engagement that is termed as *inclusive* has been defined mostly in the field of inclusive music education research. The global issue of inclusive education is outlined as the rights of a diverse group of children to comprehensive education, including an arts education and cultural experiences (UNESCO, 2005). UNESCO Salamanca Statement, which called for Education for All to educators and parents, governments and the international community, was pivotal for the promotion of inclusive education policy and practice (UNESCO, 1994). Key recommendations included enrolling all children in ordinary schools unless there were compelling reasons for doing otherwise; involving parents and pupils in planning processes; and ensuring teacher training addresses the provision of inclusive education. At present a part of the United Nations Sustainable Development Goals (SDGs) is to “ensure inclusive and equitable quality education and promote lifelong learning opportunities for all” (SDGs UN, 2015). This is viewed as an important part of contributing to social inclusion in society and towards the universal agenda of the SDGs to wipe out poverty through sustainable development by 2030.

Jellison (2012) argues that access does not necessarily lead to inclusion, in other words, just because music is included in a music program, does not mean it will be inclusive. For meaningful and inclusive music experiences Jellison (2012, p. 67) posits that a meaningful music curriculum should be flexible and accessible, not overly specialised and student progress should be assessed; participation in socially valued roles and activities with “typical” peers should be encouraged; that self-determination is fostered where participants feel safe and secure and are encouraged to experience autonomy and demonstrate competence; and where the design, implementation and evaluation of an individualised music program is discussed with the child and the relevant guardians, carers and professionals significant to the child’s life.

Multiple studies suggest that meaningful inclusive music experiences also depend on positive interactions with others and that these musical experiences need to be enjoyable and rewarding to have a beneficial impact. Furthermore, direct positive interactions require structuring by a teacher to establish an attitude or culture of inclusion in a group (Hallam, 2010; Jellison, 2012; Nordlund, 2006).

3. Music and Disability

In recent years, the academic turn to viewing music as a social process (Clarke, 2005; DeNora, 2000; Small, 1998; Turino, 2008) has opened the way for research into music’s transformative and connective functions within society. Amongst the body of work being conducted in the areas of psychology of music and sociology of music, studies have looked at music as a resource for improving personal wellbeing (DeNora, 2000; MacDonald, Kreutz, & Mitchell, 2013); as a communicative medium in which people can share time and space (DeNora, 2015); and as a transformative practice through which health and disability statuses can be challenged and understood differently (Carlson, 2013; DeNora, 2007; Lubet, 2009; MacDonald et al., 2013; Stewart, Tucker, Williams, & Haaheim, 2017; Straus, 2006). Inclusive music-making has also been researched from the perspectives of social science and critical theory (Bakan, 2009, 2014; DeNora, 2015; Howe, Jensen-Moulton, Lerner, & Straus, 2016; Lubet, 2009; Mckay, 2013).

Lubet (2009) argues that difference is not something to be excluded but rather diversity in music education and society overall is important because it strengthens the larger community as a whole. As an ethnomusicologist and music and disability scholar, Lubet draws on the argument that in Western societies musical skill is judged based on accomplishment and virtuosity, and thus those deemed not good enough are excluded from the musician status or even musical opportunities. In comparison to Western cultures, which tend to see music as an art object, produced by specialist artists—John Blacking’s (1974) assertion that the many have been made unmusical so the few can be more musical—ethnomusicology studies have documented a multitude of cultures around the world that view music as a more participatory and social activity. Lubet (2009) asserts that including those who are differently abled or not highly proficient in music theory and performance will give everyone the opportunity to benefit from the experience of music-making and enjoying music as a social activity.

His view of *social confluence* (Lubet, 2011), that a disability/ability is not a fixed status but rather is fluid and in relation to performance of ability converges with DeNora’s (2007, p. 185) view that health and illness statuses take experiential significance from their location in wider systems of meaning, materials and practices. She argues that disability can be reconfigured in relation to practices, materials, beliefs and values. These perspectives imply that the process of disability becoming normalised can manifest through accessibility and creating a “level playing field” for interactions between people with different abilities.

Inclusive music education research has contributed to thought and practice which emphasises children with disabilities and learning difficulties alongside their “typical” peers learning together in environments where self-determination is fostered. These structured teaching practices aim to lead to positive musical experiences for all participants. Social science perspectives on inclusive music and music and disability uncover the socially constructed aspect to the challenges faced by people with disabilities. The significance of this for people's lives lies in creating a level playing field in society from the perspective that difference and diversity are to be encouraged, included and celebrated; it is through efforts to *normalise* disabilities in society, that a level playing field can be created between people with different abilities.

4. Inclusive Music-Making with Consumer Music Technology, AMT and ADMIs

AMT practices at DMNI entail matching or adapting a musical instrument or sound device to a user's specific need. Utilising computer music technology, AMT practices often involve not only the tools, but also the techniques of the broad genre of electronic music. Thus, delegating musical processes to a computer system is a common solution used to address an individual's barrier to music-making with traditional musical instruments. This means performance processes can be broken down in to parts and redistributed between several performers (as opposed to a solo performer), or a single mode of interaction could control several modes of musical manipulation. This use of music technology is common in electronic music production and performance. It is especially relevant to people with disabilities, who may be able to perform or compose in a way that would not be possible without pre-constructed musical material, or through control of multiple parameters in one mode of interaction (Farrimond, Gillard, Bott, & Lonie, 2011). This is a different mode of musical performance and composition to the techniques associated with traditional musical instruments. In performances with music technology the materials are often music objects themselves, such as pre-constructed audio files (e.g., in the case of DJs, they commonly perform using vinyl records or digital music files), and where computer processes also have agency in music-making and performance (Bowers, 2002; Butler, 2014).

Devices commonly used in this area are AMTs, consumer music technology and DMIs. AMT are devices built with providing access to people with disabilities in mind, they are generally conceived as being universally accessible and utilise simple interaction modes.

These kinds of devices (such as "The Skoog", a cubic squeezable pad interface, or the "Soundbeam", an ultrasonic sensor interface) provide a mode of musical interaction that is accessible for a wide spectrum of people and involve simple movement and hand gestures that most people can participate in. However, as some participants in DMNI workshops expressed, they can also conversely have a negative and stigmatising effect. In certain cases, participants did not want to use a device that differentiates them from other musicians, or use an interface which is very simplified or "toy-like".

Consumer music technology are readily available, simple to use, generic music technology interfaces. These devices are built with an able-bodied target market in mind and are often not accessible to a wide spectrum of users. However, with the assistance of a workshop leader or community musician, these devices can be adapted or used to facilitate music-making in a way that can include people with different types of abilities.

There is also the growing availability of open-source computer and sensor technologies, which are highly customisable to a user's specific requirements, and thus afford great potential for unique and bespoke designs catering to an individual's specific needs (Jewell & Atkin, 2013). Despite these kinds of devices' high level of customisability, they require specialist expertise to build, operate, and maintain. Thus, although open-source technology is increasingly low-cost and accessible, they are not in fact *open* to many users with disabilities or the music community groups they perform with (Samuels, 2015). For settings where speed and directness of connectivity and ease of configuring and mapping is prioritised (for example in a community music workshop), consumer music technology and mainstream devices (e.g., at DMNI one of the most popular being music applications for the "iPad") may be selected over more advanced and bespoke device set-ups. This is because of the time constraints of DMNI weekly workshops, as well as due to community music facilitators lacking the required expertise in DMI design and making.

Much of the academic literature on AMT and music technology in inclusive music-making focus on the accessible devices which provide access to users with different and unique abilities (Andersson & Cappelen, 2014; Anderson & Hearn, 1994; Gehlhaar, Rodrigues, Girão, & Penha, 2014; Matossian & Gehlhaar, 2015; McCloskey, 2014; Oliveros, Miller, Heyen, Siddall, & Hazard, 2011) or to document devices, and experiments in this area (Farrimond et al., 2011; Frid, 2018; Jewell & Atkin, 2013). Some researchers have undertaken ethnographic studies into people's experiences of the use of AMT in inclusive music contexts (McHale, 2015; Samuels, 2016). A distinction can be made here between projects that provide access to music making, typically in projects that involve the creation of ADMIs or AMT, and those which encourage inclusive music-making in settings which bring together people of different abilities aiming to contribute to social inclusion and meaningful music experiences.

5. The Drake Music Project Northern Ireland

DMNI employs trained community musicians (called access music tutors) for inclusive music workshop provision to day centres and community groups across Northern Ireland and to host inclusive ensembles at its three studios in Newry, Belfast and Derry/Londonderry. The workshops can be a mix of people of all abilities, but can also be held in Special Educational Needs and Disability (SEN/D) schools or groups that provide support for people who live with the same disabilities or challenges. In addition, DMNI provides one-to-one music tuition through composition workshops. The range of musical ability in DMNI workshops also varies between workshops and group. Some participants have no musical experience and others are proficient instrumental musicians. Others have music technology experience but are not instrumental musicians. Some participants, through attending DMNI workshops over several years, have gained a high level of ability and understanding about the modes of interaction possible with music technology interfaces and can be considered electronic musicians. This illustrates how diverse the activities of DMNI are; the range of workshops provided are not uniform in size, age group, range of abilities, musical experience or community group.

There are six common identifiable stages to the composition process in DMNI workshops, which may happen across one session or several, depending on the group and the project:

1. Icebreaker group activity or discussion;
2. Setting a goal for the session through discussion and consensus;
3. A piece of music, song or soundscape is composed through discussion and musical improvisation. This process entails building up different parts (tracks/recordings) step by step, much like the processes of electronic music production. Consumer music technology and AMT are used with the access music tutor supporting certain musicians that to play music with them;
4. The parts are structured and mixed through discussion and critical listening;
5. The composition may then be arranged for performance with performance interfaces mapped and adapted to perform the music;
6. Once the composition and arrangements for performance are complete, an event may be organised to present the work to a public audience or to participant's family and friends.

This process is led by the access music tutor who is editing and structuring the music on a laptop or computer system synchronously. Decisions are made collaboratively by the group, so the access music tutor also has the role of discussion moderator aiming to elicit the thoughts, impressions and ideas of all group members. This process aims to facilitate independence of choice in each participant, even when that person may not have functional independence in the music making.

DMNI CEO Michelle McCormack expressed what she feels are important qualities in her access music tutors:

> Somebody who can actually go in and hold people's attention and in our work as well, somebody who'll go in and take that few minutes longer than they want to take when it comes to the coffee break, to listen to that person who has very slow speech, and hear just that wee bit they want to tell on how that impacted on them, or take that minute to say "did that actually go the way you wanted it to go?" rather than walking away and thinking god that was great, that switch worked and I'm happy. (Samuels, 2016, p. 31)

She emphasises rather than technical skills, that communication and an attitude of inclusivity are key. This is because they can lead to actions that give people with different abilities in DMNI workshops the space as well as at times the encouragement to be creative, compose, and perform with music technology. As Michelle's interview indicated she was hesitant to place too much emphasis on the role of the affordances of technology in inclusive music making. Throughout my study I found that it was not in the design of music technology devices that made them accessible to use and provide access to music making. Rather, meaningful music-making emerged through the interrelations between the access music tutors, workshop participants (which included people of all abilities) and the music technology interfaces in the workshop environment.

5.1. Ethnographic Methodology

Returning to my central research questions, which I investigated throughout my study, I spent over one year conducting ethnographic research at DMNI, beginning with a sixteen-week training course to become one of their access music tutors and moving on to being a part of over fifty community workshops. I established a research methodology of participant observation and semi-structured interviews to understand the ways in which people experienced using music technology in inclusive music-making contexts. In total, I conducted thirty recorded semi-structured interviews, and held many unplanned and informal conversations that I recorded in my field notes with people from all areas of engagement with DMNI.

I have considered the possibility of detrimental consequences for my research-subjects arising from their identification by name and I have discussed this with the individuals involved in my research. Some suggested that I use their real names, or only their first name. I also considered the impact my work may have on DMNI and the participants involved. Thus, I informed research-subjects (and in certain cases their guardian/carer) about the aims and implications of my research and received verbal consent for formal interviews and informal discussions.

I collected the perspectives and experiences on the use of music technology in inclusive music workshops from workshop participants, access music tutors, parents and carers of participants and other DMNI staff through these semi-structured interviews and informal conversations. I also conducted participant observations as an access music tutor whilst engaging in facilitating workshops in the DMNI studios and with community groups in different settings across Northern Ireland, which included community centres, social care centres for people with disabilities, residential and non-residential SEN/D schools for pupils who require special assistance to attend schooling.

The interview data was thematically coded and my field notes were thematically analysed. In this article I discuss major themes in relation to the research questions: music technology as a facilitator and a barrier, the social effects of music workshops, and issues related to ADMIs. These are explored through examining the experiences and perspectives of the access music tutor's and workshop participant's perceived challenges and benefits they gained from the music-making at DMNI.

Ethnomusicologists and sociologists of music have long engaged in an understanding of music as a social activity (Blacking, 1974; DeNora, 2000; Small, 1998; Turino, 2008), rather than as reified object. A relational, social understanding of music-making as human activity demands understanding the social relations between individuals, and the creative processes and techniques as they emerge in practice. Furthermore, there are human and non-human agents (technologies) of change through which these processes are enacted.

Electroacoustic composer, improviser and music theorist John Bowers (2002) argues that ethnography is the most appropriate method to understand the dynamic systems comprised of human and non-human agents through which music emerges, in his case, specifically in improvised music using computers and machines; because to understand the organisation of the music, one needs to understand how participants coordinate their activities within such performance ecologies.

Other scholars have employed ethnographic methods in the field of ethnomusicology to investigate the intertwining of processes of performance, composition and improvisation through individual professional electronic musicians in Berlin (Butler, 2014); from the anthropology of music, the localised practices of radio broadcast and the ways in which people imagine and understand radio; the contradictions of artistic legitimacy and authenticity when avant-garde computer music becomes institutionalised (Born, 1995) and from a range of music studies from ethnomusicology to popular music studies to explore the theoretical terrain of "technoculture"; how practices with technology culturally informs and influences aspects of everyday life and musical experience (Lysloff & Gay, 2003).

Gabriella Coleman (2010) in her review of ethnographic approaches to the study of digital culture asserts that trends in new media theory have come under scrutiny by anthropologists for the presumption that digital technologies for holding sweeping visions of a homogenous and global digital age. The fact that digital media and practices surrounding new and emerging forms of communication and media production effect the way people are able to represent themselves and interact is evident, however ethnographic inquiry into a variety of practices with digital technology show the necessity of pushing against narrow presumptions of a universal human experience of the digital medium (Coleman, 2010, p. 487).

One group of people that experience exclusion as part of their experience of the internet and digital technologies are people with disabilities. Faye Ginsburg's (2012, p. 113) study of creative media practices and the inclusive creative engagement an online virtual world such as "Second Life" provides people with disabilities shows that these media forms afford participation in social practices that might not be otherwise available to people who face exclusions from everyday social life. What Ginsburg's work on people with disabilities using Internet-based media show is that the capacities of digital media, rather than standardising media content and homogenising culture, enable significant interventions in our understanding diversity of people's unique abilities.

Goggin and Newell (2007), discuss the paradox of inclusive technology, which is developed with disability as the driver, but because of a lack of processes of critical analysis and evaluation, result in actually producing exclusions for disabled people. Furthermore, they comment that those "who have an interest in the technology, who are the actors, can tell us what we need to know about the strange and contingent ways that technology is created" (Goggin & Newell, 2007), echoing the commitment in the field of Disability Studies to see people with disabilities themselves as the experts on their own lives (Davis, 2000).

I have employed ethnographic methods to understand the perspectives and experiences of the access music tutors and participants involved in DMNI. In addition, I also draw on my own experiences and observations in the field to understand the processes of music making, and the potential affordances and barriers created by specific devices.

6. Music Technology as Facilitator and Barrier

Music technology are the primary tools at DMNI used for music-making with participants who often have unique abilities and do not find traditional musical instruments the most comfortable or effective way to participate in music making. At the same time, many workshop participants and all access music tutors responded in interviews that music technology was often the greatest barrier to facilitating a social activity in the group workshop context. Three main barriers other access music tutors and I encountered repeatedly were: 1) failures of technology, 2) failures in communication, and 3) becoming "stuck behind the screen".

Failures of technology include all technical failures related with the workshop equipment and computer system, e.g., the laptop computer crashing, or issues interfacing music technology devices to the computer system; failures in communication were between access music tutor and participants or the overall group; becoming "stuck behind the screen", which was a phrase commonly used amongst access music tutors, denotes the condition of becoming engrossed in editing audio on the laptop computer at the expense of engaging with the people in the room. Each of these problems can cause the breakdown of musical activity in workshops.

Instances of the failure of computer-based music technology (without a computer there is no Digital Audio Workstation [DAW], which is software where all of the music-making is edited, mixed, arranged, and structured in DMNI workshops) highlight the contradictions and contingencies of practice surrounding the very music technology devices that have been previously discussed as affording great accessible potential for people with disabilities. Whilst providing access, they also raise a problem of dependency: when the music technology fails to function can all of the workshop participants still engage in music making? Does the workshop experience shift away from being enjoyable and meaningful for those involved?

Failures in communication between the workshop participants and the access music tutor involve the challenges surrounding listening and engaging the participants in dialogue, aiming to elicit ideas and creative input into the project. Time constraints and equipment failures cut sessions short. Access music tutors also described how their emotions, mental state, and motivations influenced the outcomes of using a piece of music technology.

In the DMNI workshop context the affordances of tools alone cannot have an enabling effect without an access music tutor making efforts in dialogue and structuring the session to include all participants in the music making. From this perspective, any piece of technology (whether digital MIDI controllers, or a DIY solution to adapt an acoustic drum kit) can potentially be used in an accessible way by people of different abilities. It takes discussion and effort arrive at a place where participants can attempt using music technology devices or new forms of adaptations of equipment and thus see if the matching of interface to an individual is an appropriate one. Moreover, through discussion, self-determination in the music-making and roles each participant takes in the workshop is fostered and each person can be included in the creative process. Conversely, access music tutors acting alone without conducting dialogue and consulting others creates a clear barrier to music engagement. Thus, here questions surrounding dependency of the workshop participants on the access music tutor can also be raised.

Access music tutors identified a common phrase they used of being "stuck behind the screen" to describe the main negative tendency in a facilitator's behaviour in DMNI workshops. Access music tutors described this tension they experienced between facilitating the flow of the workshop and technically managing the music and equipment which was connected to the computer system. In an interview with an access music tutor, Damian, he emphasised that connection through eye contact with the participants was the most important factor to sustain throughout a workshop. He also commented on trying to get away from "being stuck behind the screen" as much as possible, relating it as a factor that detracted from the overall group musical experience.

During my time as participant-observer access music tutor I accumulated some experience of the barrier between the access music tutor and participants that can be created through interaction with Digital Audio Workstation (DAW software). There are many things to attend to: recognising whether participants are engaged, ensuring music technology devices are functioning, editing audio recordings and facilitating the music-making process. This is especially challenging when the workshop sizes are larger. From the interview responses with workshop participants I found that the level of communication and the perceived flow of the workshop contributed to the participant's perception of the workshop's overall success.

7. Music Technology-Based Workshops with Social Effects

During DMNI workshops, when a participant is not able to use the interaction mode of a particular device, the access music tutor will try to work with them to adapt that device in a way that would make it possible for the participant to use it. This could be as simple an improvised and creative solution as fixing a weight to a drum stick to give the participant more power to strike a hand drum with, or it could be using an ultrasonic sensor ("The Soundbeam") via a converter adapter connected to an iPad to provide a participant who finds the touchscreen interface inaccessible a different means of interacting with the iPad music applications.

One ensemble I was a part of during my field work was called "The Wired Ensemble", known to its members as "Wired". It is the longest running ensemble at DMNI. The participants work with the access music tutors through discussion and the breaking down of musical processes into stages, so they can perform through music technology devices, recording layers of compositions into a DAW on a laptop computer.

As Farrimond et al. (2011) highlight, contemporary music technology follows Moog's (1988) description of a modular system consisting of three main determinants: (1) the sound generator, (2) the interface between user and sound generator, and (3) the visual reality of the overall instrument. Each of these determinants can be modified or replaced, and so for people with unique and specific requirements, each determinant can be customised to meet the need of a particular user. In workshop sessions with "Wired", the sound generator exists as software installed on the computer accessed through the DAW application. Access music tutors can change the voices of synthesisers quickly with a massive range of sonic possibilities. Although the ensemble has fluctuated in size and membership over the years three core members are Phillip, Tim and Mary Louise. Philip was one of the founding members of Wired when it was formed in 1995:

> Yeh, I named it the Wired Ensemble. I wanted it to be called "Wired for Sound" but we decided together Wired Ensemble. The first person I contacted at Drake was Michelle. My music teacher contacted me, and then I contacted Michelle. My music teacher knew that I couldn't sustain a rhythm, that was all. (Samuels, 2016, p. 91)

The technologies and techniques used with this group are exemplary of the practices with music technology at DMNI. Moreover, being in the ensemble plays a large part in the different ensemble member's lives. Mary Louise expressed her feelings about DMNI (Samuels, 2016, p. 91):

> From an early age I always loved music. I always thought when I was older I would be able to play musical instruments. My family bought me several musical instruments but unfortunately due to my disability I wasn't able to, so it was the best day of my life at that time when Drake music was brought into my school….I have been with Drake music now for 23 years I can play any musical instruments through technology. I look forward to the Drake workshop every week, we have performed at so many venues over the years it's so amazing, it's a big part of my life.

Tim also related to me why the workshops were so important to him via email: "I love Drake because I can compose music with my friends. I can appreciate music more at home now" (Samuels, 2016, p. 91). Tim, Mary Louise and Philip each shared with me in their interviews that DMNI has provided them with a space for an opportunity to compose and express themselves with music. It has also enriched their musical experience outside of the DMNI workshops in different ways. Philip for example produces his own music at home and Tim enjoys listening to music at home. Furthermore, they shared other extra-musical benefits they have gained such as improving confidence, attaining a sense of achievement, an opportunity for forming meaningful social relationships; long-term friendships with other people with different abilities. Both Mary Louise and Tim attend other community arts and community-based activities and have a busy schedule. DMNI activities encouraged them to seek out other creative and artistic activities that they could engage with in the wider community. Thus, the activities at DMNI have a broader positive impact on social inclusion for the participants that extends beyond the workshops, with this impact extending over many years and sometimes decades.

Public performances of musical work also play a part in the activities of DMNI. Workshop series often culminate in a public performance. The Wired Ensemble members found performance the most enjoyable and rewarding part of their musical experiences at DMNI. Participants who were involved in workshops in community centres, often for a series of eight or twelve sessions, also shared how the workshops had impacted them. Participants shared their excitement and sense of achievement from being involved in the event and collaborating as a group. Participants also all responded positively that they had felt a stronger sense of community and enjoyed collaborating with their peers and friends through music. Throughout the workshops I was a part of, almost all participants responded they had felt a sense of success and achievement through rehearsing and organising their own parts and performing live.

Music Therapy research has identified performance as affording participants the feeling of being able to give back to the community and having one's talents and creativity valued and praised (Ahessy, 2015, p. 149). Through the process itself, performance promotes cohesion within a group as relationships are created and sustained through musicking with others (Ansell, 2010, p. 168). In addition, performances have been found to promote a sense of achievement and self-worth in the participant (Turry, 2005). Furthermore, Stige, Ansdell and Elefant (2010, pp. 174–176), in a volume exploring music used therapeutically through community-based practices that promote wellbeing and participation (Community Music Therapy), put forward the view that musical performance affords an opportunity for individuals to perform beyond themselves, to break out of the habit of simply being themselves to discover who they are and who they are not, affording the potential for individual transformation. At the same time, social collaboration follows on from musical collaboration (ibid). In this way a group promoting all participant's ability to participate creates a musical community for everyone involved. Through this, participants gain the opportunity to gain extra-musical, social skills.

8. Bespoke ADMI Designs

As discussed previously in this article, there are a growing number of projects by researchers and music technologists into the area of ADMI design (Anderson & Hearn, 1994; Andersson & Cappelen, 2014; Frid, 2018; Gehlhaar et al., 2014; Matossian & Gehlhaar, 2015; McCloskey, 2014; Oliveros et al., 2011; Samuels, 2015). A DMI or interface is an *open technology*, meaning it can be highly customisable, even bespoke designed, and can be adapted to different sensor input types and modes of interaction (Jewell & Atkin, 2013). The technology used in these kinds of devices are often open source (referring to computer software for which the original source code is made freely available and may be redistributed and modified), so knowledge and designs can be shared freely or built utilising knowledge and equipment anyone can obtain or purchase. For projects which involve participants with diverse ranges of abilities, these kinds of digital solutions to musical interfaces are flexible and can be designed for a particular group's specific requirements or adapted to suit an individual's unique needs. However, despite these kinds of devices' high level of customisability, they require specialist expertise to build, operate, and maintain.

In March 2015, towards the end of my field work with DMNI, in collaboration with Dr Franziska Schroeder at Queen's University Belfast, Dr Brendan McCloskey, an independent ADMI designer at the time, and Dr Michelle McCormack, CEO at DMNI, I conducted an experiment into "critical making" (Ratto, 2011) through an ADMI design event. Under the theme "Designing Inclusive Interactions", this three-day event connected nine student composers, engineers and interaction designers with five musicians from DMNI, to work collaboratively in teams to design, build and perform improvised music with DIY ADMIs. Matt Ratto (2011) builds upon the possibilities offered by open source software and hardware and explores how "making" can supplement and extend critical reflection on the relations between digital technology and society. He defines his experiments as "critical making": a mode of materially productive engagement that is intended to bridge the gap between physical and conceptual exploration (Ratto, 2011).

His research can be likened to the way in which practices surrounding DMI design, creation and performance challenge traditional musical ontological questions such as: what counts as a musical instrument (or a musician); what constitutes a musical performance; and what is musical communication? Thus, a central concern of the critical design research methodology I employed was to explore whether inclusive practices with DMIs and the development of ADMIs can be said to challenge exclusionary views and preconceptions about people with unique and different abilities.

The event resulted in the creation of five prototype ADMI interfaces co-developed by teams of DMNI workshop musicians and student interaction designers. The devices were built through a participatory and user-centred design process. The event culminated in a public concert of two pieces of improvised electronic ensemble music performed by all of the design event participants.

Interviews were conducted with selected audience members directly after the performance. One question focussed on their feelings about the central role of the DIY ADMIs in the music making. All audience members responded positively in the way that the music-making was perceived as authentic and meaningful. One audience member, whose musical background and preference is classical music and who had no experience of playing or composing with digital technology expressed that the musical expression and musicianship was different to what he was used to but no less engaging or valid in his opinion. He told me that he saw great value in the music that he had witnessed and that the shared atmosphere from the ensemble and the audience was similar to concerts he had experienced with traditional musical instruments.

I also interviewed a student composer who had attended the performance. The student composes using recordings sequenced in DAW software and so is acclimatised to electronic music production techniques and practices. His impression from the concert were similar to the previous respondent's. His response did not mention the technology however. He focussed on the feeling and atmosphere that the music created for him. When probed to describe more he explained how he had felt that it was not simply the music but he could sense through the project real relationships had been formed in the teams. Other audience members agreed that they had experienced a feeling of collaboration, sense of enjoyment, and that they had felt performers and audience had gained something meaningful from the experience.

All DMNI workshop musicians responded that they had found the experience enjoyable and rewarding. In addition, all participants found the three-day time constraint impacted the initial plans and the actual devices achieved. Many of the DMNI workshop musician's ideas could not be implemented, or due to technical issues, features had to be reduced to finish a device robust enough to be performance-ready. However, interview responses indicated that they found it exciting to perform live and had a sense of achievement and confidence gained from the project.

One participant responded that the bespoke device had provided her access to playing an instrument with keys. This was something she had tried previously but had been told by a piano teacher was impossible for her to do. When she was invited to join the project initially she was hesitant and did not feel she would be able to contribute. After the performance however, she was very encouraged and related that she had gained confidence to work towards further musical engagement and achievements.

Common responses that the nine student interaction designers shared was that the opportunity had expanded their vision of what kinds of projects they could apply their skills and expertise to. All but one of them had never considered accessible design or inclusive music as an application of their expertise before the project. Furthermore, they found the project rewarding and that it allowed them to collaborate and work with people who they usually would not have the opportunity to socialise with. A final point of development the student interaction designers felt they had gained was in communication skills by learning to communicate their expertise and bout their area of specialisations with diverse groups of people.

The "Designing Inclusive Interactions" design event created a space where DMNI workshop musicians, students and professionals engaged in a collaborative process resulting in a sharing of experiences garnered from a variety of perspectives. Dialogue between interface designers and DMNI workshop musicians allowed the core of the accessible devices' design process to be one which was transparent and inclusive of all parties throughout the project, resulting in an improvised musical performance, which was a shared achievement between all participants. The public audience was also introduced to the concepts and importance of accessible design and inclusive music-making and student designers engaged with new potential ways of utilising their specialist knowledge.

9. Conclusion

In this article I have discussed my ethnographic study with DMNI, a charity that provides inclusive music-making workshops through the use of AMT. My central research questions throughout the study were: 1) To what extent does the design of devices exclude certain users from engaging with music technology? 2) In what ways can inclusive music-making with music technology contribute to the lives of participants with different abilities? I explored these questions through my methodology of participant observation and interviews to elicit the perceptions and experiences of the access music tutors who delivered DMNI workshop and of workshop participants, who were often people with disabilities and different ways of working with music technology tools.

A key finding was that consumer music technology devices that were not designed to be accessible to a wide spectrum of users could be made accessible through adapting them with other devices or different sensor interfaces more suitable for people with unique abilities and specific needs. In addition, devices created with the intention of being accessible and universal were often not used, and consumer music technology devices were preferred even in spite of the adaptation solutions required to utilise them. This was because some DMNI workshops participants preferred to use devices which were not viewed as being made for people with disabilities and rather wished to use mainstream devices.

In many instances, music technology actually became the biggest barrier to music making, especially when devices or computer systems failed to operate or required troubleshooting in the workshop session. Furthermore, the music-making and recording of compositions in DMNI workshops are structured through DAW software on a laptop computer. The *pointer* graphical user interface mode of interaction does not best lend itself to creating social interaction with people in the immediate workshop environment as the facilitator's focus is required on the computer screen, rather than being focussed on engaging with the workshop participants. All access music tutors identified this as being the greatest barrier to creating inclusive and meaningful musical experiences.

Towards the end of my study, I employed a methodology of critical making (Ratto, 2011) through curating an event in collaboration with DMNI and Queen's University Belfast in ADMI design. This event saw the creation of five highly-customised and bespoke ADMIs created through a user-centred and participatory design process. Yet, after the three-day project was completed the devices were never again used. I found that this was because although the designs of the devices were conceived to be highly accessible and provide a high level of usability and independent musical expression for the user, they were built using technology that was inaccessible to DMNI access music tutors, who did not have the specialist knowledge and expertise necessary to utilise and maintain these devices "on the ground" in community workshops. Thus, this finding indicates that the use of music technology at DMNI is accessible not solely due to the features and affordances built into the design of the device itself, but rather in the positive attitudes shared by access music tutors and workshop participants to find creative solutions together in DMNI workshops.

The workshop participants I was able to work with through my study are extraordinary individuals, many with profound challenges in their lives. However, through DMNI workshops they displayed and developed characteristics such as perseverance, resourcefulness, creativity and imagination, and interpersonal skills. In this article I raised a question of whether DMNI workshops create and dependency between workshop participants and the music technology devices they use and between access music tutors and the workshop participants, which is necessary for the workshop participants to engage in music making. Part of the DMNI mission statement is to enable people with disabilities to independently compose and perform their own music, through the use of music technology. How can we understand the levels of independence and dependence involved in music-making in DMNI workshops facilitated by access music tutors and music technology devices?

The music-making takes the form of computer-based music production projects, utilising similar tools and processes to contemporary studio-based musicians and producers. In many situations DMNI workshop participants may not have functional independence in the music making. The facilitation of access music tutors, through dialogue, aims to provide the time and space for individuals with different ways of experiencing music and working with digital tools to input their opinions, preferences and creative ideas. Through this process, the workshop participants foster self-determination both creatively, in artistic and musical choices, and socially in which roles they wish to take in the workshop. Multiple participants responded that they gained confidence from DMNI workshops which translated into their engagement with music and art activities outside of DMNI and also in other areas of their lives. Independence in the DMNI context is not an attribute that an individual either has or does not have, rather it can be seen as something inherently social and relational; when it is enacted it is recognised as a social accomplishment and achievement.

The second research question I address in this article is: 2) In what ways can inclusive music-making with music technology contribute to the lives of participants with different abilities? I have argued that access to music-making for the participants in DMNI workshops contributed to social inclusion beyond the remit of the workshops. Workshop participants expressed how DMNI has provided them with a space to compose and express themselves through music. This has also enriched their musical experience outside of the DMNI workshops, in certain cases over several decades.

Not all workshops are able to run continuously long-term. This is due to DMNI's reliance on public funding and fundraising, which determines what they can offer to individuals and community groups. Participating in DMNI workshops over many years has encouraged certain participants to seek out other creative and artistic activities in the wider community. Thus, I have argued that the activities at DMNI have a broader positive impact on social inclusion for these participants that extends beyond the workshops, in certain cases with the impact extending over many years.

DMNI workshops, through promoting all participant's ability to participate, become a musical community for everyone involved in which participants have the opportunity to gain extra-musical benefits. Participants expressed some of these as: self-confidence, a sense of achievement, social skills, the opportunity for creating friendships and meaningful social relationships.

Acknowledgments

I would like to acknowledge and thank the Drake Music Project Northern Ireland. In particular, because they are named in this article (but not excluding all the other incredible individuals involved in the project): Michelle, Mary Louise, Damian, Tim and Phillip. I would also like to thank Dr. Franziska Schroeder and Sonic Arts Research Centre and Professor Fiona Magowan, Queen's University Belfast.

Conflict of Interests

The author declares no conflict of interests.

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COGITATIO

Social Inclusion (ISSN: 2183–2803)
2019, Volume 7, Issue 1, Pages 164–172
DOI: 10.17645/si.v7i1.1651

Article

Publicly-Researchable Accessibility Information: Problems, Prospects and Recommendations for Inclusion

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Submitted: 28 June 2018 | Accepted: 25 September 2018 | Published: 31 January 2019

Abstract
Despite worldwide attempts to improve accessibility for consumers with disabilities, barriers still exist that exclude persons from consumer participation in daily life. Although legislation and lawsuits have addressed this issue, marketplaces designed for able-bodied persons are commonplace with minimal accessibility standards tied to costs rather than the needs of this overlooked group. The present article examines a seemingly obvious, but understudied aspect of inclusion: the provision of publicly-researchable accessibility information. Ironically, businesses and public venues may create accessible spaces, yet fail to provide the level of detail needed by consumers with disabilities when planning a shopping excursion, dinner and entertainment, or travel and overnight stays. That is, the provision of factual accessibility content has lagged and is not required by law. This article reports on an exploratory study in the United States that examined the accuracy and completeness of publicly-researchable accessibility information for restaurant and entertainment venues in a large metropolitan area in the Northeastern United States. Observations were gathered from websites and social media of specific venues, as well as travel rating services like TripAdvisor. Findings were mixed. While some venues provided full and factual accessibility information, others revealed just the opposite both in online and follow-up telephone interviews. Implications are discussed along with recommendations for future study.

Keywords
accessibility; consumer planning; disabilities; information; online

Issue
This article is part of the issue “People with Disabilities: The Overlooked Consumers”, edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

1. Introduction

Within the last several decades, worldwide attention has focused on providing equal rights for people with disabilities in all areas of life including employment, education, access to politics and justice, and full inclusion in cultural events, leisure and sports. One example of global collaborative effort is found in the Convention of the Rights of Persons with Disabilities (CRPD; United Nations, 2018). According to its website, the CRPD is an international disability treaty for creating legislation and policies around the world that embrace the rights and dignity of all people with disabilities. It reports using the Americans with Disabilities Act (ADA) as a model and applies many of the ADA’s concepts within the treaty to build and strengthen the rights of persons with disabilities worldwide.

However, civil rights laws addressing the needs of persons with disabilities have offered a promise of inclusion that has not yet been fully realized. While built environments have increasingly added more accessibility features, accommodations can differ greatly from one location to another. Such differences are likely to prompt persons with disabilities to thoroughly prescreen the businesses that they patronize. Unfortunately, convenient and easy-to-use accessibility information can be difficult to locate either online or in person when needed. This article attempts to address this gap through an initial study of accessibility information sources.

Since there is no standard requirement for publicizing accessibility information for commercial businesses, consumers who want to prescreen businesses may find that description of facilities, parking, and other accommodations vary substantially when viewed online or discussed with employees. When companies provide minimal or no training in addressing actual customers' accessibility needs, incomplete and incorrect information may be provided leading to unsatisfactory experiences and exclusion from parts of the consumer experience. Such an information gap raises an understudied problem in disabilities studies: the varied and often missing publicly-researchable accessibility information.

This article reports on an exploratory study in the United States that addresses the question whether clear, correct, predictable, and personalized accessibility information is available from businesses patronized by consumers with disabilities. The study collected information posted online regarding a venue's accommodations, followed up by personal phone calls and visits. This manuscript also introduces the concept of "accessibility messaging", presents the findings, and offers recommendations for policy regarding the provision of information regarding public venue accessibility.

2. Literature Review

Throughout the last several decades, civil rights laws such as the 1990 ADA, the 2006 CRPD (United Nations), and the 2015 European Accessibility Act (European Commission) mandated that public places become accessible for all. Much progress has been made as increasing numbers of persons with disabilities have felt welcomed and included in public spaces (Baker, Holland, & Kaufman-Scarborough, 2007). While mobility accommodations are increasingly part of new building designs, sign language usage, closed captioning, large print materials, and food allergy accommodations are also anticipated in the public marketplace. Considerable efforts have also been undertaken to design websites that are accessible to persons with disabilities, especially if screen-reading software such as JAWS for Windows are used (Kaufman-Scarborough & Childers, 2009; Ritchie & Blanck, 2003; Schaefer, 2003; WEBAIM, 2018).

2.1. Disabilities and Inclusion

As members of a group, organization, or society, people are thought to experience a set of identifiable basic needs: belongingness, self-esteem, control, and meaningful existence (Williams & Nida, 2011). In order to meet those needs and attain life satisfaction, they may seek to be included, building relationships when they join and choose ways to become involved. Factors beyond their control may limit if, how, and whether they can be included. That is, they may be restricted from participation and excluded from part or all aspects of membership (Baumeister, DeWall, Ciarocco, & Twenge, 2005; Wan, Xu, & Ding, 2014). Exclusion can be experienced in many ways, such as simply not meeting criteria for membership like a minimum grade point average. It can also result from not meeting societal standards and expectations regarding abilities to perform. Unfortunately, the results of failure to meet inclusion criteria can also include being ostracized, banned, or stigmatized based on collective norms and values of the members' cultural preferences or society.

The concepts of social inclusion and exclusion are foundational building blocks in disabilities studies. Built environments can become "enabling" or "disabling" based on a designer's understanding of accessibility, when they ignore it, or when they seek to exclude persons with disabilities. Workplaces and educational institutions can disable their employees and students when attention is not paid to accessible communications, mobility needs, and various sensory issues such as multiple chemical sensitivities (Vierstra, Rumrill, Koch, & McMahon, 2007). When the marketplace is considered, store, mall, and online shopping designers may select options that enhance or limit accessibility when an ableist approach is adopted (Bromley & Thomas, 1993; Davis, 2003).

2.2. Disabilities Research and Models: Moving from Exclusion to Inclusion

The public environment has come a long way from a prior focus on disabilities exclusion. Persons with disabilities had often lived separately from society as people to be avoided, feared, protected, and even institutionalized rather than being part of public life (Goffman, 1963). An accompanying language also developed as persons "became" their disabilities and assumed labels such as blind, deaf, lame, epileptic, and mute rather than simply being persons with disabilities.

Early disabilities scholars analyzed the experiences, care, and stigmas that persons with disabilities experienced as "Disabilities Studies" emerged as a multidisciplinary area of academic interest. The medical model and the social model had been predominant in past theoretical research (Chouinard, 1997; Imrie, 1999; Oliver, 1990; Shakespeare, 1993, 2013; Shakespeare & Watson, 2001). More recently, a modern model has emerged called the affirmation model of disability (Swain & French, 2000). Each model offers a unique lens based on how persons with disabilities are perceived in terms of their social identity, their experiences, and their inclusion in society. Each will be considered briefly.

The "medical model" assumed a society in which persons with disabilities are excluded and isolated (Llewellyn & Hogan, 2000). It is rooted in "ableism", or an expectation that individuals who participate in society are typically able-bodied (Chouinard, 1997). Based on this perspective, the "built environment" would be constructed drawing on attributes of normalcy, requiring that persons with disabilities should either be "repaired" in some way or simply not participate in the activities of everyday life. This approach, which Swain and French (2000) term a "tragedy model", results in buildings and accompanying infrastructure whose designers did not anticipate the inclusion of persons with disabilities (Paar & Butler, 1999).

A contrasting approach proposes that society itself may be at fault and can be fixed, amended, and constructed in new ways that attempt to include all persons. This "social model" focuses on common elements of the built environment that can become welcoming and open to all. Such an approach set the stage for civil rights laws guaranteeing accommodations in public spaces such as schools, shops, religious institutions, and entertainment venues. When goals of access become predominant, the built environment can be required to create spaces of inclusion where persons with disabilities can function comfortably and effectively (Oliver, 1990). As a result, persons with disabilities are perceived as expected participants in the marketplace seeking "consumer normalcy" by being included in regular marketplace transactions (Baker, 2006; Baker, Gentry, & Rittenburg, 2005).

Finally, the affirmation model proposes that persons with disabilities are thought to celebrate their lives and view their disability through a positive lens. While building on the social model, this contrasting approach emphasizes individual value and identity, control of healthcare alternatives, and the positive experiences of persons with disabilities. This perspective of empowerment challenges one view of normality and instead considers persons with disabilities as participating in creating their own lifestyles, cultures, and identities (Swain & French, 2000).

2.3. Uneven Progress: Inclusion and Exclusion and the Exchange of Meaning

While public policies, academic studies, and charitable efforts have attempted to ensure access in the marketplace, actual information about accessibility options such as large print menus, sign language, and ramps content does not appear to have been uniformly regulated nor presented in a standardized format worldwide. For instance, the ADA mandates accessibility in public marketplaces but does not apparently stipulate that businesses provide advance information about marketplace accessibility in their online, print, and interpersonal communications.

As one might expect, consumers with disabilities have a greater need for certainty and factual information regarding their abilities to plan activities in advance. They report consulting a variety of sources, such as a venue's own website, Facebook page, and other travel-related rating services such as TripAdvisor and Trivago yet report mixed results. Photos of attractive restaurants and hotels may be provided along with various activities in entertainment literature, yet significant information gaps are noted by public advocates who offer rating services (Disabled Foodie, 2016). Public spaces may state that they are "handicapped accessible" and post an accessibility icon on their media. However, the quality of information may fail to address the specific needs of potential patrons, such as seating with other patrons, recorded messaging, braille, hearing assistance, service animals, and other aspects of accessibility. Moreover, employees are found to vary considerably in their training and expertise in serving persons with disabilities (Baker et al., 2007).

3. Problem Statement: Inclusive Information for Consumer Accessibility Evaluation and Choice

Consumer decision-making theory tells us that individuals rely heavily on information in making market place decisions. That is, individuals may extract, process, and use information in selecting stores, making purchases, and patronizing service-based businesses (Bettman, 1979; Bettman, Luce, & Payne, 1998; Johnson & Levin, 1985). These studies provide evidence that when a specific need or requirement is very important to a consumer, they will spend additional time and effort in searching for needed information, processing it, and using that information to create a set of acceptable venues called a "consideration set". Such a decision process may prompt someone with mobility disabilities to pre-screen shopping venues for needed accommodations such as ramps, elevators, and handicapped parking. Consumer evaluation and choice, however, can be compromised when relevant information is missing. As a result, a consumer with disabilities may find themselves excluded since an accurate evaluation cannot be made.

3.1. Accessibility Messaging

This manuscript introduces a concept called "accessibility messaging", that refers to the information indicating the availability of accommodations provided by in the marketplace or by specific venues. For instance, stores, museums, or shopping malls might develop brochures and web sites that describe the mobility accessible entrances, the use of sign language interpreters, and the availability of large-print materials and recorded information. Universities might additionally provide information on closed captioning options, opportunities for notetakers, alternative test formats, and online materials prepared with transcripts and formats compatible with screen readers (Betts et al., 2013).

In addition, there has been a significant growth in information, reviews, and ratings posted by third-party sources such as city guides, hospitality services like Trip Advisor, Facebook, and Yelp, interest groups such as the Food Network and Open Table, and other web-based services such as Google. It is important to note that these third-party sources may collect partial or dated information, such as exterior photos from Google Maps or paid advertisements that selectively provide information to a limited set of venue characteristics.

3.2. A Typology of Accessibility Messaging

Ironically, accessible built environments can become "disabling" environments when their messaging fails to provide needed information causing their elimination from the consideration set for potential consumers. We anticipate that patterns of accessibility messaging can be analyzed using the following typology (Kaufman-Scarborough, 2015):

- Universal inclusion: A venue is accessible and consumer information provides a complete description of access;
- Unintended exclusion: A venue is accessible, but accessibility information is incomplete or difficult to obtain;
- Selective inclusion: A venue is partially accessible with a complete description of access;
- Rejected exclusion: A venue is not accessible and does not provide accessibility information.

This typology is based on the inclusion/exclusion dichotomy but recognizes that there may be differing degrees of access for persons with disabilities. In the first case, a venue is classified as having "universal inclusion" if it welcomes consumers with various types of abilities and disabilities, using the principles of universal design or design for everyone. Additionally, the venue attempts to provide thorough information or a way to obtain it, such as advising the consumer to reach out in advance. This is in contrast to "rejected exclusion", in which a venue appears to be designed based on ableism, effectively rejecting those who are not able-bodied. Moreover, accessibility information is ignored and a lack of welcome is communicated.

The remaining two classifications present a middle-ground in which inclusive design and/or accessibility information is not complete. The first, "unintended exclusion", attempts to specifically consider venues that offer accessible facilities but do not communicate it thoroughly. They are the primary focus on this study since it is their information that appears to deny inclusion or may cause consumers to exclude themselves. "Selective inclusion", on the other hand, refers to venues that have chosen specific disabilities to accommodate, perhaps in response to legal mandates, but they have ignored the needs of consumers with other disabilities. For instance, some venues have emphasized readily visible accommodations such as ramps, automatic doors, and elevators in addressing mobility needs, but may report not considering patronage by consumers with invisible disabilities such as hearing, vision, and neurological impairments.

4. Methodology

An exploratory study was conducted at a major University in the Northeastern United States in Fall 2016. Student observers in an upper-level undergraduate Retailing class collected observations of public accessibility messaging provided by businesses in a major metropolitan area. In preparation for the study, the student observers first read academic and practitioner articles illustrating the information that consumers with disabilities reported as important when evaluating businesses to patronize. They next attended a training session providing insights into the anticipation, selection and identification of sources of accessibility information. They were asked to record their observations using a standard rubric and requested to focus on whether the information they collected would be sufficient for persons with disabilities to confidently patronize the venue.

The standard rubric was used by all student investigators. In addition to providing a detailed narrative of their findings, they were required to complete a standard table investigating accommodations for a minimum of five disabilities: mobility, vision, hearing, food allergies, and sensory. The table provided several accommodations drawn from the literature and practical writings on access such as ramps and automatic doors, bright lighting, sign language, gluten and peanut free, and perfume and smoke free. Students were asked to rate each area they discussion on a scale of 1 (worst) to 10 (best) on perceived accessibility.

The investigation in this study considers two type of "public accommodations", restaurants and entertainment venues that come under the jurisdiction of Title III of the ADA. A place of public accommodation is a facility whose operations affect commerce and falls into one or more of twelve specific categories defined by the government. Two of the twelve categories characterize this research: 1) places that serve food or drink (restaurants and bars), and 2) places of exhibition or entertainment (theaters, stadiums, arenas). For this study, disabilities access is measured against the ADA of 1990, the Standards of 1991, and the revised standards of 2010. They are described in detail in the ADA National Network Disability Law Handbook (Brennan, 2013).

4.1. The Student Observer Scenario

All student observers were asked to select one restaurant and one entertainment venue for evaluation based on the information provided online by the venues themselves and other third-party sources. They were also asked to make a confirmation phone call and/or visit to each selected venue to evaluate accommodations related to mobility, hearing, vision, sensory, and dietary impairments. To increase their involvement with the assignment, all student observers were given the scenario below:

> Suppose you are a junior executive at a large multinational company. You have been assigned to host a team of five guests from another division of your company who have never been to [the local major city]. Your planned itinerary includes dinner at an upscale venue and an evening at a local entertainment venue such as a concert or a major league sports event. About a week before the visit, your manager stops by to alert you that at least one of your guests has

> a hearing impairment and another occasionally uses a wheelchair due to a mobility limitation. You quickly go online to check specific accessibility for the venues you are considering. You also check travel sources like TripAdvisor and Trivago for ratings and reviews. What level of detail should you expect to find to help you plan a successful visit by the team?

4.2. Sample of Venues

A total of 37 student observers participated in the study, each collecting data from one restaurant and one entertainment venue that they had chosen for the study. While 75 observations were submitted, the final sample of 52 venues were used in this analysis. The remaining observations were omitted due to overlap, duplication, or incomplete data. An overall total of 33 restaurants were analyzed in the final sample. They included global and national chains as well as small local venues. The 19 entertainment venues included a variety of formats, with the majority focusing on major sports facilities. Others were museums, libraries, and movie theaters.

5. Analysis

Ideally, all 52 venues would have indicated that their messaging indicated universal inclusion. However, the data revealed considerable variability across the venues although some patterns were identified. Some of the venues were found to excel in providing accommodations, while others were actually in violation of the ADA. For instance, venues were identified that denied access for service animals, failed to offer usable ramps and automatic doors, neglected to consider the importance of proper lighting for persons with visual impairments, and ignored the needs of persons with hearing impairments in communicating independently with employees.

5.1. Evaluation of Observed Acceptable Outcomes

First, the 11 large entertainment venues in the sample primarily included nationally-recognized museums and sports complexes. Each clearly excelled in extensive accommodations, providing supportive and knowledgeable staff plus detailed downloadable information. Since stadiums and convention centers are often prominent places of public accommodation, they are required to adhere to the comprehensive accommodations required by both national and potentially global standards. Additionally, public interest and third-sector organizations have also established detailed guides concerning stadium access for persons with disabilities. An example is found in Accessible Stadia (2003) available online by the Football Stadia Improvement Fund. Venues such as these clearly illustrate “universal inclusion”.

One student observer made the following assessment of a prominent athletic facility in a major United States city:

> After reviewing the information available on the website of Lincoln Financial Field, they seem to be very accommodating to all kinds of disabilities. They also have very detailed descriptions of all the rules and services provided, stating: “We welcome members of our disabled community to Lincoln Financial Field, which is fully compliant with the Americans with Disabilities Act”….Lincoln Financial Field has highly advanced, top of the line hearing assistance devices and also has Braille guides for the entire stadium located at all Guest Service booths.

5.2. Evaluation of Observed Unacceptable Outcomes

The remaining 41 eligible cases consisted of both large and small venues that did not provide full accessibility information and varied in the accommodations they discussed in publicly. Essentially, both unintended exclusion and selective inclusion overlapped since various combinations of partial accessibility and partial public information tended to be the most common finding. One common finding indicated that the majority typically indicated some information of mobility, ramps, and automatic doors in their promotional materials. Consumers with other disabilities and special dietary needs instead were asked to contact the venue for information and special assistance. Other venues appeared to downplay the effectiveness of their accommodations, potentially becoming rejected by consumers due to a lack of information.

For example, assessments of the Cheesecake Factory restaurant chain indicated that “the little information presented on their website was not enough to make a patronage decision”. One student observer pointed out that several negative reviews on social media revealed that persons with other disabilities were apparently not accounted for:

> One person claimed that their wheelchair could not fit into the handicapped restroom, while another person claimed that they could not get their wheelchair through the front door, because they only had a revolving door. People who were deaf or hearing impaired reported that they had a very unpleasant experience there and it was more difficult for them than other restaurants. One customer who had poor vision reported that the restaurant is too dark at night, and that it made it impossible for them to see.

5.3. The Impact of Technology

In contrast, movie theaters were found to offer complex accommodations due to innovations in entertainment and movie theater technology. Theaters reported having options for hand-held closed captioning, amplification and enhancement of audio, and even narration of the action on the screen. For instance, AMC offers assistive listening devices (ALDs) plus “CaptiView”, a personal closed captioning device that can be attached to a mounted cup holder as indicated in the AMC assistive moviegoing guide (AMC Theatres, 2018).

In addition, the student observers reported that theater managers noted that many accommodations were not listed online since they required personal discussion with staff and often advance reservations. Given the growing numbers of customers who gain movie, time, and ticket information online, providing full online information is a convenient opportunity to communicate welcome to persons with disabilities. In addition, AMC also reported offering "sensory friendly films" at specific times, welcoming persons with autism to comfortably get up, move about, and "dance, walk, shout, or sing". This specific option confronts the isolation of the medical model approach by offering an innovative approach that includes persons whose disabilities may manifest in less conventional behaviors.

5.4. Informal Efforts to Provide Accessibility

As might be anticipated, small local venues were found to made informal yet effective efforts to provide access, such as reading menus to customers who were blind and using informal hand gestures to persons who could not hear. While such efforts do not conform to typical formal accessibility laws, the reports indicated that customers were quite satisfied with the accommodative service although the information was not available to those attempting to prescreen in advance.

For instance, one student reviewed a local city's public library where she was employed. She reported a lack of online information such that:

> A person with a disability would have no idea what to expect from the library based on the website. A phone call to the library was useful in clearing up questions and would be enough to reassure me that the library is handicap accessible. Based on my experience working at the library I know that there are several limitations including one bathroom without wall rails, books that are out of reach, and poor lighting in certain areas. Also, there are aisles that would be difficult for a person using a wheelchair or walking aid to navigate due to books and tables.

Finally, some venues appeared to have made no effort in communicating their accommodations to potential patrons. Information was totally absent from some globally-prominent restaurant chains as seen in Table 1 below that provides "examples of information omissions". Others had incomplete information or according to the student observers, employees who were not trained to discuss access questions. For instance, employees reported not being certain whether service animals were allowed. In discussing a small local restaurant, one observer commented that "after reviewing their web and social media outlets I was disappointed to learn they do not do a good job explaining they are wheelchair accessible".

5.5. Variations in Publicly-Available Accessibility Information

The observations collected in this study offer preliminary evidence that publicly-available accessibility information varies widely among public venues that consumers may want to patronize. Particularly troublesome are businesses that comply with all/some accessibility guidelines, yet they ironically do not do a consistent job informing their customers about it. For instance, one student observer could not find complete information on TGI Fridays Restaurant online in the Northeastern United States but was able to use a UK website found at disabledgo.com to complete a pre-evaluation of this global chain. The site is simple to use with a variety of accessibility icons that enable a thorough understanding of the accessibility of a specific business.

Large national sports venues could probably be called the "gold standard" both of multi-disability accommodation and of accessibility messaging. Online accessi-

Table 1. Examples of information completeness/omissions.

Example	Venue	Situation
1	Sports stadium in major NE citie in the United States	Multi-disability access, accurate information
2	TGI Fridays Restaurant	Good/fair access, incomplete accessibility information online, full accessibility information on disabledgo.com
3	Applebees Restaurant (2 locations)	No online accessibility information; some accommodations
4	Cheesecake Factory	Online mobility access information, complaints on Twitter by several customers with disabilities
5	Olive Garden (Darden)	No online access information, spacious, helpful staff, accommodates on food allergies
6	Small local Taproom/Grill	No online access information, employees taught to informally accommodate patrons with disabilities

bility guides appeared to be the standard with detailed information on various types of disabilities support by staff. The venues gave a clear impression that accessibility is a priority and that they are experienced in working with patrons in advance to plan their visit. The notion of prior planning was emphasized so that the customer and any companions would be well-prepared.

5.6. Limitations

Since this is an exploratory study, it is necessary to briefly discuss its limitations. The study is not representative of the full range of entertainment and restaurant venues in the tri-state area where the study was conducted. As a next step, a sample should be drawn systematically from a comprehensive listing of all businesses within specific categories in order to ensure representativeness. Additionally, observers must be required to examine all possible communications channels from telephone calls and personal visits, to websites and social media posts.

6. Recommendations

The present article offers a call to research specifically examining the availability of information about accessibility in built environments. It calls to question whether there are policies in place that require that information about accessibility be provided to potential patrons. Today's intense and rapidly changing communications environment is full of potential to increase message accessibility to persons with disabilities. Just as universal design principles can be implemented in designing products, stores, and venues that can be used by all, an extension to "universal communications design" can enhance message transmission for a wider number of people who have access to and can respond to information conveyed by combining several styles in order to maximize the opportunities to transmit meanings.

6.1. Requiring Standard Formats for Accessibility Information

The article asks whether accessibility information is available online as needed by patrons with disabilities. It raises the question to policymakers worldwide whether accessibility information should be coordinated and/or regulated so that a standard format and a verified set of disabilities needs are required to be addressed.

Since there are sets of disabilities icons, words, accommodations, and symbols that can be universally adopted, the actual use of standard formats would seem to be a straightforward outreach for various types of public venues. In addressing this suggestion, policymakers might develop and test similar information summaries to determine whether they actually add to the search process and decision-making success of persons with disabilities.

6.2. Reimagining Consumer Communications to Include Persons with Multiple Types of Disabilities

Persons with disabilities routinely participate in growing numbers throughout educational, business, and social contexts. Yet our study found that consumers with physical disabilities in general were better accounted for then other types of disabilities. While the sporting and movie venues displayed considerable accessibility for persons with vision, hearing, and sensory disabilities, venues such as restaurants appeared to address ADA-required accommodations primarily through mobility-based assistive aids. Our study leads to the recommendation that accessibility messaging must address the concerns and questions of persons with multiple types of disabilities so they can prepare for participation in the marketplace. This expectation should lead us to ensure that our messages, our media, and our accommodations enable inclusive communications to take place maximizing understanding, response and feedback.

Future study is needed that identifies the exact information, its format, and the options that require advance notice. Disabledgo.com provides a useful starting place by considering the standard system of icons used in representing desired venues. According to the website, the icons and definitions were developed from information suggested by actual persons with disabilities. In addition, venues that provide online access to real-time assistance can examine whether online "chats" are provided in usable formats for persons with various communications abilities.

6.3. Expanding the Access/Information Typology to a Continuous and Measurable Format

This initial study also demonstrates that the classification typology used in this study is not detailed enough to evaluate the variations in accessibility accommodations and information communication. Some specific disabilities such as those requiring special preplanned assistance may not be able to predict the full detail needed in their accommodations for each customer. Additionally, the information needed by certain consumers may vary based on the type of media typically used and its capabilities for full access. Additional academic study is needed that integrates the opinions of persons with disabilities.

7. Conclusion

This article reports on an exploratory study that examined the accuracy and completeness of publicly-researchable accessibility information. As anticipated, accessibility messaging is not complete across various types of venues but instead varies based on the venue type as well as the apparent commitment to accessibility. In addition, accommodations may vary based on venue-specific assistive technology as shown in the example of movie theater technologies. Finally, businesses who are compliant may increase their opportunity to include consumers with disabilities by conducting an assessment of company and third-party information and identifying both gaps and opportunities to communicate a welcoming environment.

Conflict of Interests

The author declares no conflict of interests.

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COGITATIO

Social Inclusion (ISSN: 2183–2803)
2019, Volume 7, Issue 1, Pages 173–179
DOI: 10.17645/si.v7i1.1594

Commentary

Equal Access to Make Emergency Calls: A Case for Equal Rights for Deaf Citizens in Norway and Sweden

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Submitted: 1 June 2018 | Accepted: 24 September 2018 | Published: 31 January 2019

Abstract

It is stipulated that deaf citizens have equal right to use social services as other citizens. One social service is the access to make an emergency call. Deaf citizens who cannot hear and use a signed language to communicate have to make emergency calls in another way rather than relying on listening and speaking via a telephone. However, the possible ways to call are not the same for deaf citizens in all countries. This commentary shows that there are options dedicated for deaf citizens to make emergency alarms in both Norway and Sweden: via telephone typewriters, Short Message Service, and Video Relay Service, although the design of the respective options differs between the countries. However, it is argued that deaf citizens in Norway do not have equal access to make emergency alarms as other citizens in Norway, whereas the situation for deaf citizens in Sweden may be seen as equal compared to other citizens in Sweden, although there still are limitations.

Keywords

alarm call; deaf; equal rights; interpreter; Short Message Service; signed language; SOS phone; telephone typewriters; Video Relay Service

Issue

This commentary is part of the issue “People with Disabilities: The Overlooked Consumers”, edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

1. Introduction

It is stipulated that deaf citizens have rights equal to other citizens. This stipulation can be found in the United Nations document Conventions on the Rights for Persons with Disabilities (United Nations, 2006). Citizens' rights are specified in The United Nations Universal Declaration of Human Rights (United Nations, 1948). Both documents emphasize that all citizens are entitled to equal protection against discrimination, which includes social and cultural rights, as well as protection against language discrimination. Likewise, denial of social rights is prohibited by the European Commission in The European Accessibility Act (European Commission, 2015) and The European Disability Strategy 2010–2020 (European Commission, 2010), where common accessibility requirements for social services is emphasized. Although there are several documents declaring equal rights for all, barriers still exist, such as a lack of provision of service, problems with service delivery and a lack of accessibility for people with disabilities (World Health Organization & World Bank, 2011).

One social service is to provide facilities to make an emergency alarm and call for help to an emergency dispatch centre since access to emergency services can be seen as a right for all citizens (see Paredes, Fonseca, Cabo, Pereira, & Fernandes, 2014). However, to make an alarm call assumes that you have access to, and can use, the existing services (cf. Chiu, Liu, Hsieh, & Li, 2010; Constantinou, Ioannou, & Diaz, 2017; Power, Power, & Horstmanshof, 2006). However, compared to a telephone call to make an alarm by auditive and vocal resources, this may be done in another way for deaf people who use a signed language. In this commentary, an ongoing activity in real time by signed and/or spoken language is referred to as *to make a call*. Whereas *to make* *an alarm*, is an activity that is done by text exchanges and/or not in real time.

The possibility for deaf citizens to use social services has changed over time. Likewise, the ways deaf citizens have been treated have also changed over time. Historically, people who are deaf have been considered to be, and have been treated as people who need help from someone who can hear (Fredäng, 2003; Kermit, 2006; Raanes, 2013) who can interpret for them in order for them to take part in society and to communicate with hearing people (Kermit, Mjøen, & Olsen, 2011; Lundström, 2001). According to these views, those who then interpreted for deaf people did so without remuneration, and it was often a relative, a hearing friend, or helpers from church (Lundström, 2001; Roy, 2002). Hence, deaf people were dependent on someone who could hear and who was willing to make sacrifices for them. Consequently, at that time, the only way for deaf people to make an emergency alarm was to depend on others. These limitations to make an alarm to an emergency dispatch centre show that deaf people historically have not had the same civic opportunities as other citizens.

Today, deaf people have access to call as a citizen's right in both Norway and Sweden (Haualand, 2011). However, even though these countries are geographically close, the solutions available to deaf people to make emergency alarms differs. Moreover, the national organization of emergency dispatch centres are not the same in the two countries. In Norway, there are different alarm numbers depending on the type of alarm (i.e., fire brigade, police, doctor, or ambulance), whereas Sweden, as a member of the European Union (EU), follows a stated standard where one centre in the country allocates the emergency dispatch centre (see European Emergency Number Association, 2018). Consequently, in Sweden, SOS Alarm is responsible for allocating all such resources.

1.1. Ways to Communicate: Signed, Spoken and Written Languages

According to deaf people, to speak and listen through a telephone is not optimal if they cannot hear. Therefore, deaf people may use other solutions to make phone calls if their preferable first language of communication is a signed language. Compared to people who hear and have another spoken language than the majority language, hearing people could make an emergency call by the use of a "bridge language" (i.e., a lingua franca), for example English, in Norway and Sweden, or they may communicate by using some simple words in negotiation. People living in a foreign country can probably also learn the majority language over time. However, people who are deaf cannot learn to hear.

Signed and spoken languages differ: signed languages are visual/gestural languages, whereas spoken languages are aural/oral languages. Many spoken languages have a written form, which signed languages such as Swedish Sign language (SSL) and Norwegian Sign language (NSL) do not have in the same way (see for example Grushkin, 2017; Hole, 2007; Regeringskansliet, 2006). Thus, it can be challenging for deaf people to read and write written language (Regeringskansliet, 2006) in an urgent situation. However, in signed languages, some spoken words, for example addresses, names and other words, may instead be finger spelled letter by letter.

The modalities of signed and spoken languages also rely on different grammar features, which means that signs cannot simply be transformed into spoken words (Bergman & Nilsson, 1999; Regjeringa, 2008). Adding to this, signed languages, as every other language, have cultural aspects. The cultural aspects of signed language include the way it is performed and accepted in society. When comparing the acceptance of NSL in Norway and SSL in Sweden it becomes apparent that both countries protect their respective signed language by law. In the case of Norway, NSL was accepted and recognized as a full language in 2008. Norwegian law stipulated that NSL deserved a higher official status, and the language should be supported for persons who use NSL (Regjeringa, 2008). In the case of Sweden, SSL is protected by the Swedish language law, which states that people who are deaf should have the possibility to use SSL (Svensk författningssamling, 2009). Moreover, the public has a special responsibility to protect and promote SSL. In 1981, the government acknowledged SSL as (preferably) the first language of deaf people in Sweden, whereas spoken and written Swedish can be a second language (Regeringskansliet, 2006).

2. Options for Deaf Citizens to Make Emergency Alarms

Many countries all over the world, including Norway and Sweden, have regular emergency dispatch centres. However, the options for deaf citizens to get in contact with an emergency dispatch centre differ from citizens who use spoken languages and call by an ordinary telephone when making an emergency alarm. Deaf citizens require other solutions to make emergency alarms.

2.1. Making an Emergency Alarm by Telephone Typewriter

Deaf people can communicate from a distance using text, which can be done with a telephone typewriter (TTY) by exchanging text in real time. The exchange is organized via texted instructions by signalling "go ahead" and "over and out", in other words, the communication is structured and is not simultaneous, as in face-to-face interaction. Although TTY can be used to make emergency alarms in both Norway and Sweden, there are radical differences in their design.

In the case of Norway, deaf citizens can use TTY to make emergency alarms, though it must to be done through a Text Relay Service where an operator relays the written text from the deaf person to the emergency dispatch operator, and vice versa, via a special alarm number (Call-It, 2018; Telenor, 2018). In Sweden, deaf citizens can make an alarm call directly to the emergency dispatch operator via a special number using TTY (SOS Alarm, 2017).

However, one drawback of making an alarm through TTY is the aspect of time, as it is an urgent situation (Forslund, Kihlgren, & Kihlgren, 2004). Additionally, since written text is not a deaf person's first language, it may be cumbersome to write an urgent message in a precarious situation (cf. Chan et al., 2010, p. 137). Findings from emergency calls to the Swedish emergency dispatch centre also show a risk of misinterpretation when people use a foreign language, and also when there are cultural differences that operators may not understand (Forslund et al., 2004). Alarms from a TTY to an emergency dispatch centre could also be challenging because the information conveyed may be "meagre" (Forslund et al., 2004), so it may be difficult for the operator at the emergency dispatch centre to decode what is written. Thus, TTY may be used in acute situations, but the messages will be short, unsecure, and time consuming. Above all, there is the question of whether deaf people use TTY to communicate from a distance at all, since presumably few deaf citizens neither have a stationary TTY nor have downloaded the TTY application on their mobile or smart phone.

2.2. Making an Emergency Alarm by Short Message Service

With the influence of a more digitalized and mobile society, deaf citizens in both Norway and Sweden can make an emergency alarm by a sending a short message service (SMS) from a mobile phone or a smart phone to an emergency dispatch centre. In Norway, a pilot project has been launched offering participation to deaf citizens (Direktoratet for samfunnssikkerhet og beredskap, 2018). The project runs officially until 2019, but has not yet been evaluated (Direktoratet for samfunnssikkerhet og beredskap, 2016). In Sweden, the option to make an emergency alarm by SMS has been available since 2012. However, as is the case in both Norway and Sweden, deaf citizens must register their mobile phone with the national emergency dispatch centre beforehand (Direktoratet for samfunnssikkerhet og beredskap, 2018; SOS Alarm, 2017).

Some of the barriers that occur when using TTY are also relevant when making an alarm via SMS; written language may be challenging to write and read in urgent situations, and the messages are short and may be meagre. Another issue when using the SMS service is that citizens must have money on their phone and also coverage in the case of Norway (Direktoratet for samfunnssikkerhet og beredskap, 2018). Additionally, both the Norwegian and the Swedish emergency services note a similar issue: the SMS may be delayed or disappear if coverage from a network operator is poor (Direktoratet for samfunnssikkerhet og beredskap, 2018; SOS Alarm, 2017). Therefore, the service provider in Sweden recommends that SMS may be used by deaf people only if they cannot get help from someone with "full speech and hearing ability" (authors translation from SOS Alarm, 2017). This recommendation indicates that it is not safe to use SMS to make emergency alarms and that it is preferable for deaf people to get assistance from a person who can hear if they need to call for help, which means reverting to historical and unsatisfactory solutions.

2.3. Making an Emergency Call by Video Relay Service

To communicate and make an emergency alarm using signed language is possible via a video phone through Video Relay Service (VRS). In cases of emergency, the VRS call is relayed by an interpreter who interprets between the deaf person and the operator at an emergency dispatch centre. The interpreter is able to see the person using a video phone on a screen and to hear the person using a telephone via a head set (Warnicke & Plejert, 2018). In some calls, a text exchange may also be possible between the caller from a video phone and the interpreter, i.e., a "total conversation". However, this option is dependent on the caller's video phone resources. VRS, however, is an option for deaf people that allows them to make a call by signed language in real time.

For signing deaf people in Norway, VRS calls have been an option since 2008 (Arbeids- og velferdsetaten, 2018b), and are available Monday through Friday, between 8 am and 8 pm. (Arbeids- og velferdsetaten, 2018a). In Sweden, VRS has been a regular service 1996 and is open around-the-clock (Warnicke, 2017). The Swedish VRS offers a special number for emergency calls (Bildtelefoni.net, 2018), unlike in Norway. Calling through a special emergency number, as is possible in Sweden, reduces the time spent waiting on hold. It also supports the VRS interpreter; when answering the call he/she already knows that it is an SOS call (cf. Warnicke & Plejert, 2012, 2016).

Even though deaf people can call using a signed language through VRS, there are challenges. One challenge is that the interpreter needs to manage the fact that both the deaf person and the emergency dispatch operator are physically separated and are located in different places. The interpreter thus has to manage several practical matters because of the lack of direct contact between the caller and the emergency dispatch operator, for example the organization of turns (Warnicke & Plejert, 2012). Therefore, organization also takes time since the interpreter needs to see what is signed before formulating and interpreting what is said, i.e., processing time in order to formulate and make the interpreting (Warnicke, 2018). To decode what is signed is a challenge, as the signed language is communicated through a flat screen on video phone which means that the media is two-dimensional instead of three-dimensional as in face-to-face communication. Thus, to decode a finger spelled word, for example an address or a name, is difficult and probably even more difficult in an emergency call when the situation is urgent and stressful. Furthermore, decoding can be demanding depending on the screenshot between the signing caller and the interpreter, which is affected by the surroundings the deaf party is calling from. When the surroundings or the connection are poor, the screen may be pixelated, which means that the ability to interpret is affected (Warnicke & Plejert, 2012). Hence, the organization of turns and the restricted view of the caller may be challenging for both the interpreter as well as for the deaf person. The person at the emergency dispatch centre may also be affected by these circumstances, which can lead to difficulties in understanding what the call concerns (cf. Forslund et al., 2004; Warnicke & Plejert, 2016).

Communication among deaf people via video phone observes a discourse organization that differs from a telephone call (Keating & Mirus, 2003); for instance, some information is not said because the video phone gives visual access to what is happening on the other end. In calls via VRS, there might be a discrepancy between what needs to be said and what is happening in the area around the deaf person. For example, a deaf person calling from a fire could be stressed and the surroundings could make visual contact between the deaf person and the interpreter challenging, so it would be hard for the interpreter to see what the deaf person is signing. Since the interpreter should just interpret and the operator at an emergency dispatch centre should assess what is needed, these circumstances may be precarious and possibly life threatening. To conclude, it is generally challenging for an interpreter to decode signed language from a two-dimensional screen and it can be even more difficult in urgent calls.

2.4. Solutions of Yesterday and for Tomorrow(?): REACH112 a Completed Pilot Project in Sweden

Sweden, as a member of the EU, has participated in a pilot project called REsponding to All Citizens needing Help: REACH112 (European Emergency Number Association, 2012). The project was funded by the EU organization European Emergency Number Association. The project was run between 2009 and 2012 in Sweden and tested a total conversation, i.e., a combination of live real-time text, video and voice simultaneously to make emergency calls. The calls provided visual contact between all of the physically separated interlocutors: the help-seeking party, the remote Swedish/SSL interpreter, and the operator at the emergency dispatch centre. Outcomes of the project stress a “huge social change in the target user group”, and “enormous benefits in terms of health, employability and social interaction” (European Emergency Number Association, 2012, p. 27), although it may be a question of how to sustain the services in the light of cuts from the respective central government. However, after the project was finished, this solution was not implemented as a regular service. Nevertheless, the EU is still working to integrate IP-based communication technologies and interoperability within the project “NEXt generation Emergency Services”, although aspects of making emergency calls by signed language as such are not an issue (see Nexes, 2018).

3. Do Deaf Citizen Have Equal Access to Give an Alarm as Other Citizens?

For a deaf person to be able to make an alarm, solutions designed for signing deaf persons are needed (such as TTY, SMS and video phone), and the emergency dispatch centre must be able to handle these solutions. Thus, the issue involves telecom access as such (cf. Paredes et al., 2014). Regarding the available telecom access for deaf citizens in Norway and Sweden, there are options available in both countries. These options may look the same on the surface, but they differ according to the design of the technical solutions and their availability and the structural organization of the emergency service within the countries also differ.

Making an emergency alarm using text (i.e., TTY and SMS) is an option for deaf citizens. In Norway, the TTY emergency alarm needs to go through a Text Relay Service and not, as in Sweden, directly to the emergency dispatch centre. Thus, emergency dispatch centres in Norway do not provide a direct link between the caller and the emergency operator. In Sweden, an operator at the emergency dispatch centre handles the call without an intermediator. Nonetheless, in both countries, it is possible to make emergency alarms via TTY around the clock. Another available option using text, in both countries is to send an SMS. Of course, it can be important for deaf citizens to have the possibility to make emergency alarms by text, but this option is not optimal because of the challenges with giving alarms using written text.

An equal way for deaf people to make an emergency call is for them to be able to use signed language. However, the only way deaf people in Norway can make an emergency call using signed language is via VRS, Monday to Friday, between 8 am and 8 pm. Adding to this, calling via VRS in Norway is done via a regular number, so the call may be placed in line and put on hold. Since time is restricted and the call is handled as an average call, the option to make an emergency call at whatever time needed is not equal to other citizens in Norway. In Sweden, it is an option to call using signed language via the Swedish VRS is offered around the clock. It is also an option in Sweden to call via a special number to get in contact with the emergency dispatch centre immediately. Although the VRS services in the two countries are similar on the surface, variations within the organizations show radical differences in terms of deaf peoples’ equality to other citizens. Both Norway and Sweden have different telecom access options for deaf citizens to make emergency alarms. The structures of the options do not create equality for deaf citizens in Norway, whereas the situation in Sweden is more developed, since it has a different design.

Nevertheless, there are also challenges with the Swedish VRS. In the Swedish VRS, as well as the Norwegian VRS, the deaf caller and the emergency dispatch operator lack visual contact. Visual access in emergency calls by deaf citizens can facilitate the call, and even if the operator at the emergency dispatch centre cannot understand what is signed or even understand signed language at all, the operator may get an indication of what is happening by seeing the surroundings. Through the emergency dispatch operator's greater knowledge and observation, he/she could possibly make a more correct assessment of the situation. Thus, visual contact between the deaf person, the interpreter and the emergency dispatch operator will provide a more efficient communication. As stated earlier, there are difficulties for the interpreter in decoding signed language on a two-dimensional video phone, and especially in a stressful situation. The possibility for everyone to see each other may also help the interpreter to focus on the interpreting itself and not the surrounding meta-information (see Warnicke, 2018; Warnicke & Plejert, 2012, 2016). Since every second counts, more efficient communication and interpretation can save lives. Although both the telecom access and emergency dispatch service seem to be able to manage visual contact between the interpreter and the emergency dispatch operator in Sweden, as shown in the pilot project REACH112, it is not yet provided as a regular service in Sweden.

Although there are several possibilities and solutions for deaf citizens in both Norway and Sweden based on telecom access to make emergency alarms, emergency dispatch services need to be able to manage those alarms if full equality is to be realized. In this aspect, emergency dispatch services need to offer direct communication by signed language. One solution towards the possible path to full equality is a total conversation solution, as in the REACH112-project. A total conversation solution could even be offered as a possibility for everyone, and if so, visual contact in emergency calls would not only be an advantage for deaf citizens but for everybody as a universalistic view of human functioning (cf. Jarl & Lundqvist, 2018) and to eliminate the lack of visual contact in all alarm calls.

4. Conclusions

This commentary shows that deaf citizens can make emergency alarms in both Norway and Sweden using solutions such as TTY, SMS, and VRS. However, there are differences in the solutions provided between the two countries in terms of the design, availability and structural organization of the service facility.

In Norway, deaf citizens are restricted to making emergency calls using their first language, NSL, via VRS from Monday through Friday, 8 am to 8 pm, using an ordinary number and may be placed in line and put on hold. Using written language to make an alarm is possible with TTY via an intermediator and there is a pilot project running in Norway where deaf citizens can make emergency alarms by sending SMS. However, the caller needs to have money on their phone for the SMS, and the service provider has issued a warning that there are coverage limitations. Thus, although deaf citizens have equal rights according to stipulated documents (see Regjeringa, 2008; United Nations, 1948, 2006) the conclusion is that signing deaf citizens in Norway do not have equally access to make emergency alarms as other citizens in Norway.

In Sweden, deaf citizens can call in their first language, SSL, around the clock via VRS through a special emergency number. Deaf people in Sweden may also use written language to make an emergency alarm directly to the emergency dispatch centre via TTY or SMS. Deaf people in Sweden have equal rights to make emergency alarms and calls through an interpreter, although the call will be relayed. However, a further step, and a way to overcome barriers when using VRS, may be if the emergency dispatch centre operator could also see the deaf person, so that all three interlocutors have visual and auditive contact. If all the interlocutors had direct access to each other, the interpreter's work and the operator's intervention decisions could be more strongly supported. Moreover, visual contact among all interlocutors in a call may be beneficial during emergency calls from anyone. However, full equality for deaf signing people in Sweden would be if deaf people could make an emergency call using SSL directly to an emergency dispatch operator who uses SSL as well. This is not possible today so although the situation for deaf signing people in Sweden may be seen as equal, there still are limitations.

Acknowledgements

I would like to thank Dr. Hilde Haualand, Oslo and Akershus University College of Applied Sciences, Norway, for correspondence regarding the manuscript. I would also like to thank Marie Tapper, Örebro University, Sweden, who generously commented on the text, with great enthusiasm. The current commentary was funded by the University Health Care Research Center, Region Örebro County, Sweden.

Conflicts of Interests

The author declares no conflict of interests.

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