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Resilience Governance: a good place for disabled people to shape and resist problematic resilience discourses?

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Abstract: Resilience is a concept employed within an increasing scope including ecology, security, social sciences and human psychology. It is applied to various social groups including disabled people. At the same time there are numerous critiques within and outside of the disability community of how resilience is conceptualized and operationalized. The media is a tool used to inform the public and to shape public discourses. Many discourses are seen to be in need of governance actions such as science and technology or global health including the resilience discourse. Our study contributes to the discussions around resilience and disabled people in two ways. First we add qualitative data on the narrative of resilience in relation to disabled people in Canadian newspapers. Our findings reveal very little mentioning of disabled people within the newspapers covered whereby the nature of the coverage exhibits many of the facets for which the resilience discourse is critiqued within and outside of the disability community. Secondly we use a governance lens to analyze the existing governance of resilience discourse to ascertain whether a governance of resilience discourse might be a place for the disability community to shape resilience discourses. We suggest that the existing governance of resilience discourse has to change substantially, to be able to govern resilience discourses in a way that prevents negative impacts of resilience discourses on disabled people. Given the premise of governance as used in other discourses disabled people could lead to a positive change by influencing the resilience governance discourse.

Keywords: resilience; disabled people; people with disabilities; governance; newspaper; Canada; resilience governance; governance of resilience

Resilience Governance: a good place for disabled people to shape and resist problematic resilience discourses?

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Part 1: What is resilience and what is the problem?

Resilience

Resilience is defined as a system's ability to absorb and recover from a disturbance, while maintaining the same function and identity (Holling, 1973). It also represents the ability to re-shape following a disruption; allowing it to avoid future disturbances, by reducing vulnerability. (Klein, Nicholls, & Thomalla, 2003). Historically, resilience was first a concept applied to nature, meant to examine and explain the survival and adapting mechanisms of ecosystems (Holling, 1973). The application of resilience to the human experience or human systems refers to the phenomenon of good outcomes regardless of pertinent threats to adaptation or development of an individual (Masten, 2001). According to the American Psychological Association webpage, "Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress — such as family and relationship problems,

serious health problems or workplace and financial stressors. It means "bouncing back" from difficult experiences" (American Psychological Association, 2017).

Resilience is conceptualized to entail two components, a threat and a positive developmental outcome (Masten & Coatsworth, 1998). The threat component is seen as imperative, as it is argued that individuals cannot demonstrate resilience without the overcoming a risk that threatens their development (Masten, 2001). For an individual, these threats encompass variables such as low socioeconomic status, exposure to violence, and other statistical predictors of developmental problems (Masten, 2001).

According to (Folke, 2016) "development resilience has been defined as the capacity over time of a person, household or other aggregate unit to avoid poverty in the face of various stressors and in the wake of myriad shocks. If and only if that capacity is and remains high over time, then the unit is resilient" (Folke, 2016) However, resilience is not the prevention of disturbance, but rather increasing an individual or system's endurance to disturbances (Holling, 1973). "Resilience is not a trait that people either have or do not have. It involves behaviors, thoughts and actions that can be learned and developed in anyone" (American Psychological Association, 2017). Among scholars there is still no consensus concerning the standards that can define a good outcome (Everett Waters & Sroufe, 1983; Luthar, 1991; Masten, 2001).

Critique of resilience outside the disability community

Given the ever expanding application of resilience it is not surprising that there are problems with its implementation. According MacKinnon & Derickson, 201, problems with resilience include that it ignores social relations and is externally defined by state agencies and

experts. An additional critique questions the focus on attempts to bounce back or maintain the status quo (Cretney & Bond, 2014; Davidson, 2010)

Critique of resilience from within the disability community

Critique of resilience is also voiced in relation to disabled people (Aubrecht, 2016; Ellis, 2013; Goodley, 2005; Hutcheon & Wolbring, 2013a, 2013b; Runswick-Cole & Goodley, 2013; Young, Green, & Rogers, 2008). Runswick, Cole and Goodley (2013) argued that it is important to critique resilience narratives as they are applied to disabled people because the traditional use of resilience often increased discrimination and marginalisation of disabled people. One example of such marginalization is the use of resilience to "rationalize the removal of the perspectives of university students with lived experience of disability and madness" (Aubrecht, 2016, p. 186).

To mention four critiques; one critique centres around the lack of reflection on the social construction of the outcome measures of resilience (Young et al., 2008) and on the focus on an individual's ability to be resilient (Hutcheon & Wolbring, 2013b). The burden of implementing resilience relies solely on the individual therefore the noted protective factors that can help an individual become more resilient in the face of adversity must be obtained and utilized by the individual themselves (Young et al., 2008). This perspective completely ignores the social circumstances that perpetuate these negative outcomes especially in the case of disabled people. Resilience as it relates to disabled people rarely takes into account society's role in their disablement (Hutcheon & Wolbring, 2013a). The narrative of resilience simply calls for the individual to rise above adversity. The focus on an individual's ability is called out by members of a disability resilience research project quoting various resilience definitions:

“Walsh (2003) defines resilience as “the ability to withstand and rebound from disruptive life challenges. Resilience involves key processes over time that foster the ability to ‘struggle well’, surmount obstacles, and go on to live and love fully” (p. 1). Gordon (1996) defines resilience as “the ability to thrive, mature, and increase competence in the face of adverse circumstances” (p. 1). Glick (1994) writes, “‘Resilience’ is the ability to ‘bounce back’ from adversity, to overcome the negative influences that often block achievement. Resilience research focuses on the traits and coping skills and supports that help kids survive, or even thrive, in a challenging environment” (p. 1)(Members of the disability resilience research project, 2006b, pp. 4-5).

Another critique is linked to overcoming ones difference as a form of resilience (Young et al., 2008).

To quote from a resilience toolkit produced by members of the disability resilience research project

“Disabled people have told us that resilience is about more than something that one person has and another person doesn’t have. The key message from disabled people is that resilience is a process which is on-going and that the feeling of being a resilient person is made both in terms of our relationships with other people and in terms of access to resources”.(Members of the disability resilience research project, 2006a, pp. 5-6)

Whereby resources seen to include “financial, educational, technological, medical, and employment opportunities” “assistance and access to food, clothing, and shelter to meet basic needs” and relationship, identity, power and control, community participation and cohesion and social justice (Members of the disability resilience research project, 2006a, pp. 6-7)

That being ability different is seen as a risk factor is also flagged as a problem (Hutcheon & Wolbring, 2013b) given the "normative definitions of health, wellness, and able-ness" (Hutcheon & Wolbring, 2013b, p. 240). The resistance of accepting one's body reality as a risk factor manifest itself in the form of "cripping" resilience (Hutcheon & Wolbring, 2013a), questioning the negative perspective society has on 'disability' (Hutcheon & Wolbring, 2013a). Lastly, resilience retains societal ideas of a resilient lifestyle, which often incorporates notion of independence (Hutcheon & Wolbring, 2013a). This is problematic for individuals experiencing disability that rely on assistance either through informal or formal care. These definitions pose a threat and fail to include the reality of what resilience looks like for someone with a disability (Hutcheon & Wolbring, 2013a)

Part 2: Case study: Coverage of resilience and disabled people in Canadian newspapers

Background

It is well reported that newspapers and other media influence discourses (Nord, 1988). Newspapers and other media have a large impact on individuals and are influential in creating their perspective on health and social issues. Moreover by setting the agenda and by providing an opportunity for flow of information and the emergence of new perspective (Abrams & Maibach, 2008). In addition, they provide a convenient collection of data in the sense of collecting and adhering to data (Miles & Morse, 2007). Although there are various media analysis studies on resilience such as the one looking at Australian news articles from 2006 to 2010 which concluded that the media provided excellent context and coverage on community-spirit, resilience and the importance of learning and sharing experiences (Leitch & Bohensky, 2014) and others (Bohensky & Leitch, 2013; Kaufmann, Lewandowski, Choryński, & Wiering, 2016;

Torres & Alsharif, 2016) no study has been performed concerning the resilience narrative related to disabled people. Our research question for the case study covered in section 2 was: how do Canadian English language newspapers report on resilience in relation to disabled people?

Methods

Study Design:

Framing is one way to perform a newspaper analysis (Entman, 1991, 1993). We were interested in what frames were used to describe the relationship between resilience and disabled people. Three ways of framing includes structural (Benford, 1997), content (Scheufele, 1999) and issue-specific framing (De Vreese, 2005; Spiller, 2004). We sought to see how disabled people are engaged with within the content of resilience coverage. Our content analysis focuses on how the communicator (the newspaper) frames resilience as it relates to disabled people. Persuasion is a media effect that encompasses the message, who is used as a source and the "persuadability of media consumers" (Collins, Abelson, Pyman, & Lavis, 2006, p. 91). The question is what the reader will be persuaded of after reading the coverage of disabled people within the resilience covering newspaper articles. Words are seen in general to influence perception, thought, and action (Lupyan & Clark, 2015). Words are seen to facilitate interactions (Cann & Kempson, 2017), to enable concept knowledge and to acquire abstract concepts and words are used "to create emotional experiences and perceptions" (Lindquist, MacCormack, & Shablack, 2015, p. 1). Given the power of words one question is for example what interactions with disabled people are triggered by how words are used to describe the relationship between resilience and disabled people.

Data Sources and Data Collection:

To answer the research question we used as a source the *Canadian Newsstand Complete* now called *Canadian Newsstream*, a database consisting of n=300 English Language Canadian newspapers, for its complete time range from 1980-2017. On June 7th, 2017 we searched the database for the phrase "resilience" in conjunction with "disabled people" or "people with disabilities". The obtained n= 94 newspaper articles were downloaded as one PDF file and imported into ATLAS.ti-8®, a qualitative data analysis software application for qualitative, thematic content analysis.

Data Analysis:

We employed a qualitative thematic content analysis of the n=94 articles collected to answer the research question. We first read all the articles in ATLAS.ti-8® and coded the articles for whether resilience was engaged with in relation to disabled people. In the second step we coded the articles that we highlighted in step one as engaging with resilience in relation to disabled people for the themes evident in the use of the term resilience in relation to disabled people. In step three we investigated how resilience was covered in the articles where resilience was not linked to disabled people. The coding was deductive in the sense that the top level themes we were looking for were predefined by the research question (Daly, 2007; Mayring, 2000). However, the sub-themes that emerged were not pre-set and as such could be seen as an inductive approach (Daly, 2007; Mayring, 2000). Credibility/dependability and confirmability are three trustworthiness measures (Baxter & Jack, 2008; Lincoln & Guba, 1985; Shenton, 2004). Both authors performed the qualitative analysis. To enhance credibility/ dependability the authors engaged in peer debriefing on the generation of the qualitative data. Differences in codes

and theme suggestions of the qualitative data were few and discussed between authors and revised as needed. Confirmability is evident in the audit trail made by using memos and coding functions within ATLAS.ti-8®. Regarding transferability, our methods provide all the necessary information for others to use if they decided to apply our study to for example other English language newspapers, other English language media sources or translate our keywords into other language to search non-English sources.

Limitation:

Our study collected articles searching for the explicit presence of the keywords “resilience”, “people with disabilities” and “disabled people”. Many articles could cover resilience by using synonyms related to resilience of which one can find many searching thesaurus. We chose to only look for the term “resilience” because we were interested in what meaning was attached to the very specific term which will influence the understanding of the term resilience the reader obtains. One of the critique of the discourses around resilience is that it is often linked to a narrow subset of possible meanings of resilience namely with the person having to be resilient. Synonyms already assume often a certain meaning of a term.

Results

There are over 35,533 articles in the 300 Canadian newspapers that contain the term “resilience”. However of these 35,533 articles only n=94 contained the phrases “disabled people” or “people with disabilities” two major terms used if one wants to cover the social group of disabled people. Reading the 94 articles the following themes were evident.

Articles covering resilience without linking it to disabled people

Articles did not link resilience to disabled people and no angle that would cover disabled people could be envisioned:

Within the n=94 articles, all but n=18 articles did not engage with resilience in relation to disabled people. Many of these articles mentioned resilience without any content attached to it. Numerous articles mentioned resilience in accordance with event announcements. Resilience was sometimes associated with individuals, by which they were praised for their individual resilience such as in eulogies without further elaboration on what is meant with resilience. Resilience was attributed to Canadian people, business, labour, equity groups, economy, and stores, not for profit, towns, and organizations without further elaborations. One article stated that an individual's occupation can increase resilience, whereby the article used as an example working at the Canada Paralympic Committee.

Articles did not link resilience to disabled people but the themes found could have covered disabled people as the themes found are of relevance to disabled people:

Four articles mentioned the term "community resilience". One article reprinting the throne speech of the government in 2013 indicated the government believes that community resilience can mitigate problems linked to emergencies in general and natural disasters in particular before they happen (The Canadian Press, 2013). Three articles recognized protective factors to building and increasing resilience in communities such as age-friendliness, having a network of people and getting to know your neighbours (Lieuwen, 2014; Strandberg, 2005; Telegraph-Journal, 2014) whereby communities and individuals are expected to implement these measures on their own (Telegraph-Journal, 2014). One article linked household resilience to getting to know ones neighbors and how to help each other's, (Telegraph-Journal, 2014). The

issue of mutual aid was also covered in (The Guelph Mercury, 2013). Two articles gave definitions of resilience one stating that resilience is the result of succeeding at a difficult task (Anonymous, 2016) and another that "resilience can be defined as the ability to experience changes in our lives without having our lives completely fall apart around us" (The Guelph Mercury, 2013, p. A11). One article makes the case that resilience has to be all around us because many have traumatic event but very few of them cannot deal with them (Gilbert, 2006)s.

Themes in the articles that explored resilience in connection to disabled people

Of the articles that made the connection between resilience and disabled people every single one focused on disabled people as the source of resilience of exhibiting resilience whereby different themes were linked to the narrative of resilience disabled people exhibit.

Theme 1: Resilience and the over-achiever

One article wrote about the impact of Terry Fox and Rick Hansen, two highly visible disabled people within Canadian history, who are seen by many as heroes due to their personal achievements on the attitudes regarding disabled people (Smythe, 1988). Concluding in relation to resilience: "but Fox certainly dramatized the importance of hope, ambition, and individual resilience to the disabled" (Smythe, 1988, p. 1).

Theme 2: Personal story

Articles used the personal stories of individuals exhibiting individual resilience to demonstrate the impact of resilience (Crew, 2014; Dedyne, 1994; Saper, 2006; The Province, 2016; The Vancouver Sun, 2015) One article linked individual resilience of a group of

individuals such as amputees as an example of resilience of a country (Porter, 2010). Another article makes the case that individuals require the resilience to adjust to their life and experiences following disability, (Kenna, 2012).

Theme 3: Successful in self-employment due to being individual resilient

In three articles by the same author it is argued that disabled people thrive as a result of self-employment and are more likely to be successful in running their own business due to resilience (Morton, 2008a, 2008b, 2008c).

Theme 4: Independence

Two personal articles examined individuals who were quadriplegics and how they demonstrated resilience because they gained back their independence (Anonymous, 2009b; Paterson, 2009).

Theme 5: Resilient due to bad treatment

One article explored that the resilience demonstrated by disabled people is rooted in the horrible treatment that have been exposed on both an individual and societal level (Griffin, 2010). Although this article does not focus on an individual disabled person but a group of disabled people as written the reader obtains the impression that the resilience is an attribute of disabled people.

Theme 6: Medical resilience

One article simply stated that it requires individual resilience to survive long enough, if one is suffering from medical illness or disability (Makin, 2012).

Theme 7: Mentioning disabled people in relation to resilience without defining the context of resilience

One article simply stated that one has to increase the resilience among the most vulnerable whereby disabled people are mentioned as part of the list of vulnerable groups (Ferenc, 2011). Two other articles discussed projects and organizations that were hoping to celebrate and support resilience for disabled people (Anonymous, 2009a; Block, 2002).

Discussion

Media including newspapers influence discourses (Lyytimäki, 2011; Nord, 1988; Picard & Pickard, 2017) such as governance discourses (Dyck, Volchkova, & Zingales, 2008; Trenz, 2004), executive leadership (Helms, 2008) and policy change (Shanahan, McBeth, Hathaway, & Arnell, 2008). Some note that the role of media increased in recent times (Roco, 2008). Media literacy with the meaning of "ability to access, analyze, evaluate, and create media content" (Martinsson, 2009, p. 3) is seen to contribute to "participation, active citizenship, competence development and lifelong learning" (Martinsson, 2009, p. 3) and good governance (Ali, 2006; Martinsson, 2009). Picard and Pickard set out as some of their essential principles for contemporary media and communications policymaking that it should facilitate "citizen participation in debate of issues and developments affecting society" (Picard & Pickard, 2017, p. 9), "Seeking diversity of providers and types of content" (Picard & Pickard, 2017, p. 9) and

“fostering meaningful public consultation and participation in the policy process” (Picard & Pickard, 2017, p. 10). Our findings suggest that as to the newspapers we covered a lot has to be done to fulfill the role newspapers ought to be.

Lack of mentioning:

That we obtained n=35,533 articles with the term “resilience” indicates that resilience is seen as a useful term by newspapers for their readers and that the newspapers think that their readers want to read about resilience. As such how resilience is utilized by the newspapers influences what the reader thinks resilience is and what the purpose of resilience should be. The terms “disabled people” and “people with disabilities” are two major terms used in discourses to engage with the social group of disabled people (Barnes, 1999; Chataika, Mckenzie, Swart, & Lyner-Cleophas, 2012; S. Miles & Singal, 2010). That we found only so few articles that mention the terms “disabled people” or “people with disabilities” suggests that the reader is not exposed to resilience in the context of disabled people a finding that fits with other studies that found an underwhelming coverage of disabled people in newspapers (Wolbring, 2016; Wolbring & Mackay, 2014). Furthermore, most readers will not link the topic of resilience to disabled people whether in the meaning of individual or social resilience. Of course a topic does not have to mention disabled people and terms such as disability, disablement or impairment in order for disabled people or disablement or impairment to be present somehow. (Michalko, 2009) writes about the absent-presence of disability using two types of examples. One mentions warning language such as “do up your seatbelt” (Michalko, 2009, p. 68) which assumes the danger of disability (with the meaning of impairment) as a consequence of not adhering to the warning.

Michalko in the same article also gives an example of absent-presence of disability in the social disablement sense

We walk towards a building; a flight of stairs greets us; the stairs are the only way to enter the building. We 'see' no one on or near the stairs whom we recognize as disabled. Disability is not present. And yet, if we pause and 'listen' very carefully, we can 'hear' the presence of disability in its very absence. If we 'tune our ears' to pick up the muse of our culture, we can 'hear' the stairs saying 'All can enter this building, all except you who are disabled, you are not welcome in this building. In fact, those who built this building didn't even think of you, disability, let alone expect you to show up'. (Michalko, 2009, p. 68)

Although we agree with what Michalko states, to recognize the disability (whether impairment or social) lurking in the background one needs to be literate in certain ways to recognize the unsaid or to identify what is not even unsaid as in totally missing. We submit that how resilience was covered in the articles we covered the reader is if at all conditioned, trained, made more literate to identify in other writings around resilience or see as missing disability with the meaning of impairment rather than social disablement. (Prince, 2009) asserts that disability exists in the shadows of public awareness and at the periphery of policy making. We submit that our findings suggest a conditioning of public awareness that sees the impairment flavor of disability linked to resilience and not the flavor of social disablement which in turn influences in which way given readers might influence policy making discourses.

Lack of applying an applicable theme to disabled people:

Many of the articles we found through the keyword searches were false positives with resilience not being covered in relation to disabled people although both keywords were present in the articles. Many of the articles mentioned resilience in such a way that it would not be an opening to engage with disabled people such as the mentioning of resilience only as an event announcement. However, there were a few themes around resilience in articles that could have engaged with the topic as to what it means if disabled people are the focus. In one article, the protective factor of neighborhood is mentioned "Perhaps the most important element of household resilience is this: get to know your neighbors, and discuss ways you can help each other in emergencies" (Telegraph-Journal, 2014, p. A4). This quote suggests that in case of an emergency getting to know your neighbors is a protective factor that can help you become more resilient to disaster. However, the article does not touch on the inaccessibility that disabled people face when trying to build relationships with their neighbors. For example, an individual in a wheelchair may have a hard time reaching his neighbors considering that the majority of Canadian homes are not accessible to wheelchairs (Canadian Centre on Disability Studies, 2017). In addition, the specific statistics concerning the inaccessibility of housing are not available further demonstrating the invisibility of disabled people. Nevertheless, if community building is such an imperative component of resilience, policy and governance must provide the measures that ensure that these protective factors are available and accessible to individuals experiencing disabilities. Communities and individuals are left with the burden of increasing their own resilience and acquiring the protective factors for themselves. Community resilience is covered in various articles. This coverage could have been expanded to look at disabled people as part of the community. It would not only allowed to engage with challenges to community resilience specific to making disabled people part of the community, it would also enrich community

resilience strategies more useful to resist a system that does not cherish diversity. Engaging with disabled people empowers the community to engage with the challenges of ability differences, a challenge not only faced by disabled people but by many people. (Kim, Kim, & Lee, 2017; McClure, 2017; Stevens & Marchant, 2017; Wolbring, 2014, 2016) Moreover, how a system can become resistant to efforts to decrease the acceptance of ability diversity. It might allow community resilience against a system that favors individual responsibility and negates social responsibility.

Individual resilience:

If articles explicitly dealt with the linkage between resilience and disabled people the focus was the individual resilience of the disabled person. No article engaged with societal aspects of resilience in conjunction with disabled people. Although this type of coverage of resilience fits with the American Psychological Association understanding of resilience (American Psychological Association, 2017), it is questioned substantially within the disability community as outlined earlier (Hutcheon & Wolbring, 2013a, 2013b; Members of the disability resilience research project, 2006b) (Young et al., 2008).

The notion of independence, as in doing it yourself not as in being in control, as an indication of resilience is linked to the individualistic theme in the newspapers (Anonymous, 2009a, 2009b; Hayes, 2010). Such use of the term independence is a problem as it removes accountability from society for the social reality they create for disabled people by demands for them to become more resilient (Hutcheon & Wolbring, 2013b). By engaging with disabled people the authors could have diversified the views on independence away from the focus on individual resilience to the strengthening of community residence using the term of

interdependence a term that is according to the late disability studies scholar Leipoldt discussed extensively within the disability community (Leipoldt, 2006). Indeed we submit that accepting and strengthening interdependence adds to community resilience.

Many articles that covered resilience as an individual parameter were linked to the overcoming adversity theme that disabled people must overlook their stance in society and just continue with their life. Throughout the articles, the so-what attitude was considered an ideal attitude to have towards disability. It was celebrated and considered a display of resilience. However such narrative comes with the consequence that individuals who are unable to "bounce back" are blamed (Crow, 2014, 2015), a narrative that is questioned within the disability community critique of resilience (Young et al., 2008).

Only one article questioned the usefulness of the overcoming adversity image "Many of these people, in fact, ranging in infirmity from quadriplegics, to victims of multiple sclerosis, to the blind, the deaf, and the lame, must wonder just how far the Hansens and Fox's of the world will actually improve their situations" (Smythe, 1988, p. 1).

The individualized focus we found fits with how Canadian newspapers cover disabled people within other topics (Wolbring & Abdullah, 2016) and the overcoming adversity theme is evident in many newspaper articles whereby the presence of such theme is questioned for a long time (Berger, 2008; Booher, 2010; Harnett, 2000; Howe, 2011; Kama, 2004; Myers Hardin & Hardin, 2004; Silva & Howe, 2012; Tynedal & Wolbring, 2013; Wolbring & Litke, 2012). In order to combat the individualized focus on resilience in regards to disabled people, we must account for social conditions that marginalize individuals with disability.

Conclusion

Our findings suggest that the newspapers covered influenced the discourse around resilience in a negative way for disabled people by a) rarely mentioning disabled people and by b) focusing nearly exclusively on an individual based resilience. The coverage provides no evidence to be used for societal based policy decisions on resilience in relation to disabled people. It does not give the reader any ideas as to the societal issues of resilience as they relate to disabled people.

Given the general critique of the resilience discourse voiced by the disability community and given the problematic coverage in the newspapers covered which reflects many of the critique raised within the disability community what can be done to change the situation?

Part 3: Governance of Resilience: a useful discourse for resistance?

Governance has been defined as "actions and means adopted by a society to promote collective action and deliver collective solutions in pursuit of common goals" (Dodgson, Lee, & Drager, 2002, p. 6). Frenk and Moon state that "the notion of governance goes beyond the formal mechanisms of government and refers to the totality of ways in which a society organizes and collectively manages its affairs" (Frenk & Moon 2013, p. 937). According to the European Commission "Governance means rules, processes and behavior that affect the way in which powers are exercised, particularly as regards openness, participation, accountability, effectiveness and coherence" (Boekholt et al., 2002, p. i). Irwin (2008) argues that "the study of scientific governance is broadly concerned with the relationship between science, technology, and political power—with special emphasis on democratic engagement, the relationship between 'scientific' and wider social concerns, and the resolution of political conflict and controversy"

(Irwin, 2008, p. 584). Governance is also applied to other areas such as global health whereby global health governance is seen to be achieved with a fair and equitable global governance system that is more sustainable and includes democratically distributed power (Ottersen et al., 2014). Ability expectation governance focuses on how to navigate the societal aspects of ability expectations and the impact, sustainability and utility of existing ability expectation hierarchies (Wolbring, 2017; Wolbring & Diep, 2016a). As such, if a governance of resilience discourse follows the sentiment of the discourses mentioned it could be a useful discourse for the disability community to influence the resilience discourses.

Governance of resilience discourse:

As to the interactions between resilience and governance two angles exist. Generating resilience is seen as an indicator of good governance (Nirupama, Popper, & Quirke, 2015). Resilience is regarded as a sign of adapting capacity and is seen to require a web of networks including social, economic and physical in order to operate. It is argued that it takes leadership, cooperation as well as community engagement to increase resilience (Gardner & Dekens, 2006). The notion of governance is instrumental in implementing strategies that will increase resilience particularly in fields such as psychology (Everett Waters & Sroufe, 1983). Although this might be useful for disabled people, this angle does not change the harming effects of resilience discourse concerning them.

The other angle is how to govern resilience which would include how to set up resilience in a positive way. The literature is very unclear on that angle. Very few articles thematized how to operationalize the resilience discourse. Governance is seen as a critical component of the administration of resilience especially when dealing with social-ecological systems that

constitute social, political and economic systems (Nirupama et al., 2015). Governance of resilience incorporates the ability to manage and purposefully infuse components into a system that will allow it to be resilient against a disturbance (Nirupama et al., 2015). The impact and assessment of resilience within a system is dependent on the governance and management of resilience (Nirupama et al., 2015).

According to (Folke, 2016)

“issues of distribution, inequality, and diverse aspects of power and politics in their own right were not the core in the emergence of resilience thinking. Rather, they were incorporated as part of analyses of complex adaptive social-ecological systems, reflected in the abundant resilience work on agency, actors, participation, diverse knowledge systems, learning, coproduction, adaptive management, social networks, collective action, institutions, stewardship, social-ecological innovation, transformation, and multilevel and adaptive governance of social-ecological systems” (Folke, 2016).

Folke then cites ten studies that looked at “issues of inequality and diverse aspects of power and politics in social-ecological systems and sustainability through collaboration across knowledge domains and in the continuous evolution of resilience thinking” (Folke, 2016).

However, none of the articles listed engaged with disabled people. Indeed the review on resilience by (Folke, 2016) did not indicate anywhere that disabled people have a role to play and when we searched the Ecology and Society webpage where Folke’s article was published no hit was obtained for “disabled”, “disabilities” or “disability”. Furthermore, searching the 70 databases of EBSCO All and the databases Scopus and Web of Science generated no article that covered disabled people in relation to the governance of resilience. Therefore, it seems that the resilience

thinking around inequality, power and politics is rather limited as is the area of who collaborates and what knowledge is seen as useful.

Governance of resilience incorporates multiple approaches such as risk-based approaches or assessment based approaches (Brown & Williams, 2015; Lampel, Bhalla, & Jha, 2014). These approaches differ depending on the type of system such as a political, economic system in contrast to an individual or a community (Brown & Williams, 2015).

What approach to take for dealing with resilience is an important area of governance to which the disability community should and can contribute. Given the already existing critique of resilience discourse of seeing being differently abled as a risk factor (Hutcheon & Wolbring, 2013b) the no-presence of the disability community in the governance of resilience discourse has to be changed to influence the problematic risk assumptions found within the resilience discourse. The same is true for the assessment approach. What is assessed very likely changes if one looks at a situation through the lens of disabled people.

Competing systems provide an obstacle for governance (Walker & Carpenter, 2002). There must be consensus on the objective and vision for what resilience means and looks like for that system. But such consensus should not be obtained within a framework of a voiceless disability community. The history of disabled people consist of clashes of values, perception, goals, and both problem identification and resolutions with non-disabled stakeholders (Wolbring & Diep, 2016b). The area of resilience exhibits the same clashes.

Edwards (2009) argues that resilience is not developed solely governments but built by communities and individuals (Edwards, 2009). Communities have experiences re-occurring threats and understand how to properly manage them accordingly, they can provide knowledge that will strengthen the vision and implementation of resilience (Ho, Chen, Nobuyuki, Lur, &

Lu, 2016). If resilience is meant to be built by communities than it is imperative for the disability community to be a part of that community.

As to factors identified to increase resilience the following are mentioned on the webpage of the (American Psychological Association, 2017): caring and supportive relationships within and outside the family, provide role models, capacity to make realistic plans and take steps to carry them out, positive view of yourself and confidence in your strengths and abilities, and skills in communication and problem solving, the capacity to manage strong feelings and impulses.

Importantly the webpage states that "these are factors that people can develop in themselves" (American Psychological Association, 2017). In other words, these factors reflect ability expectations of the person. It simply puts the blame on the person. We argue that most of the factors seen to support an increase in resilience listed on (American Psychological Association, 2017) need a change in society if the resilience of disabled people is to increase. The claim that individuals are solely responsible for obtaining and developing these skills to increase their resilience further supports the problematic notion of resilience in regards to disabled people. To question a few of the skill claims that the person is to obtain by themselves; how can one develop caring and supportive relationships if one cannot meet anyone? In our case study, we outlined that one newspaper article mentioned the need for good neighbor relationships and we argued that in order to have them one first has to be able to meet them which for wheelchair users often fails due to lack of access to houses. Liz Crow recently highlighted the worsening of the perception and treatment of disabled people in the UK (Crow, 2014, 2015). How can one generate a positive view of oneself and loving relationships outside ones family (and even within ones family) as a disabled person within such hostile environment, a hostile

environment that is also evident in the continuous push for eliminating of many ability differences in the pre or after birth stage (Wolbring & Diep, 2016b). How can one have confidence in ones strengths and abilities if one is unemployed; a situation very likely as even the United States of American reports less than 20% of disabled people are employed (Employment-population ratio) a number that takes into account who does not look for work and people looking for work but cannot find work (Bureau of Labor Statistics United States Department of Labor, 2018; Wolbring, 2016).

Removing any responsibilities from society and placing the burden on the individual to obtain these factors as done by the (American Psychological Association, 2017) is just one example of why the presence of the disability community and disability studies scholars in the resilience governance discourse is so important and why the resilience governance discourse has to change.

However, whether the arguments of the disability community will be listened to is uncertain even if their critique is also put forward by people outside of the disability community and applied to other social groups beyond disabled people. We have many example where an argument put forward by a certain group was not seen to be acceptable to be used by disabled people (e.g. being a sex selection prohibition proponent does not mean one is a deselection prohibition based on perceived 'impairment' proponent (Wolbring, 2003)). Nevertheless, we submit that the disability perspective is essential one for the resilience discourse and is an instrumental component of uncovering and implementing resilience in ways that it maximizes a positive outcome. The list of factors listed at (American Psychological Association, 2017) and the demand that the individual fixes the problem is a form of ability expectation oppression and ability privilege, two aspects questioned specifically within the disability community discourse

(Wolbring, 2014; Wolbring & Ghai, 2015) as part of questioning the disabling use of ability expectations and ableism in general (Campbell, 2009; Goodley, 2014; Miller, Parker, & Gillinson, 2004).

Due to the evidence-based nature of resilience, models are subjected to prove their effectiveness through models such as meeting targets and indication (Howell & Voronka, 2012). Question is who decides on the indicators and targets? When we searched "governance of resilience" or "resilience governance" in conjunction with "disabled people" or "people with disabilities" for example in Google Scholar, EBSCO All, and Scopus we could not find even one relevant article. This suggests that disabled people are not part of the academic discourse that links to the term resilience governance or governance of resilience.

According to Schmidt "the emergence of resilience could be read as a new ontology requiring or enabling new ways of thinking, acting and governing, which originates from but no longer operates within the neoliberal problematic of epistemological complexity ('never getting it right')"(Schmidt, 2014, p. 419). As is in the moment the governance of resilience discourse seems to miss the boat on how to govern, if looked at through the lens of disabled people. If governance is about "actions and means adopted by a society to promote collective action and deliver collective solutions in pursuit of common goals" (Dodgson et al., 2002, p. 6) and if good governance is about participation, (Boekholt et al., 2002, p. i), then participation should include the disability community to influence the resilience governance discourse. However, a lot of work must be done by the disability community to make this discourse a useful one for them. If one for example uses the rungs of the participation ladder proposed by Arnstein: (i) manipulation, (ii) therapy, (iii) informing, (iv) consultation, (v) placation, (vi) partnership, (vii) delegated power, and (viii) citizen control (Arnstein, 1969) our evidence suggest that disabled

people might not even be on the first rung because they are simply a non-entity in the governance discourse.

The governance of resilience discourse might be a good place to resist the prevailing resilience discourse as the resilience discourse in general and the resilience governance discourse in particular did not generate but should generate actions, policies and thought that fix the problems disabled people identified in regard to the resilience discourses.

Part 4: Conclusion

Many problems have been identified with how resilience is portrayed in general and in relation to disabled people in particular. Our newspaper data suggest that the newspaper coverage of resilience in relation to disabled people exhibits the main problems identified already as a critique of resilience discourses in relation to disabled people.

Governance is seen as important for many discourses including the resilience discourse. Given what (Folke, 2016) states about the coverage of issues such as power and inequality in discourses around resilience thinking disabled people and the disability community at large should be part of the resilience governance discourses. However, the governance of resilience discourse did not engage with disabled people so far.

Given the premise of governance (power sharing, participatory...) the governance framework might be a useful one for the disability community to use to engage with resilience and ultimately resist the existing resilience discourse and to remedy the negative implications the current resilience discourses has on them. The resistance we argue might be especially powerful, if the governance of resilience would be anchored in the governance of ability expectations in order to prevent the disabling aspects of ability expectations and ableism such as ability inequity

and inequality(Wolbring, 2010), ability expectation oppression and ability privilege (Wolbring, 2010). However, a lot of work must be done for the disability community to make this discourse a useful one for them and to move up the rungs of the participation ladder proposed by Arnstein (Arnstein, 1969) as our evidence suggest that disabled people might not even be on the first rung of manipulation yet because they are simply a non-entity in the governance discourse.

Our findings also suggest that the resilience governance discourse has to account for various pitfalls such as the non-involvement of disabled people and the lack of strategies that fix the problematic newspaper coverage of resilience as it pertains to disabled people (our findings) and very likely the coverage of resilience in newspapers in general. As to governance processes the question arises whether media portrayal is part of a good governance process. What good does it do to listen to the 'voiceless' as is envisioned in governance discourses if this voice is negated in the narrative of media that influences the public?

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