Review

Coverage of Allies, Allyship and Disabled People: A Scoping Review

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Abstract: Disabled people face many problems in their lived reality, as evidenced by the content of the UN Convention on the Rights of Persons with Disabilities. Disabled people are constantly engaged in activism to decrease their problems. However, disabled people cannot do all the work by themselves and need allies (who can be so-called non-disabled people or disabled people of a different background to other disabled people) given the many barriers disabled people face in being activists, given the precarious lived reality of many, and given the many problems in need of solving. At the same time, the expectations linked to being an authentic ally of disabled people pose many challenges and stressors and a danger of burnout for the ally. Therefore, the aim of this study was to better understand the academic coverage of allyship and allies in relation to disabled people in general, and specifically the coverage of challenges, stressors, and danger of burnout for allies of disabled people. To fulfill this aim, we performed a scoping review of academic abstracts and full texts employing SCOPUS, the seventy databases of the EBSCO-HOST and the Web of Science. Of the 577 abstracts, covering allies and allyship in relation to disabled people that were downloaded, 306 were false positives. Of the 271 relevant ones, the content of six abstracts suggested a deeper coverage of allyship/allies in the full texts. Within the full texts, two mentioned ally burnout and four mentioned challenges faced by allies. Among the 271 abstracts, 86 abstracts mentioned allies without indicating who the allies were, 111 abstracts mentioned specific allies with technology as an ally being mentioned second highest. Sixty-three abstracts covered specific topics of activism for allies. Furthermore, although searching abstracts for equity, diversity, and inclusion (EDI) related phrases, terms, and policy frameworks generated sixty-three abstracts, only three abstracts mentioned disabled people. Abstracts containing science and technology governance or technology focused ethics fields terms did not generate any hits with the terms ally or allies or allyship. Searching abstracts and full texts, phrases containing ally or allies or allyship and burnout had 0 hits, ally terms with stress* generated four hits and phrases containing anti-ableism, or anti disablism, anti-disableist, anti-disablist, anti-ablist, or anti-ableist with ally terms had 0 hits. Our findings show many gaps in the coverage of allies and allyship in relation to disabled people especially around the barriers, stressors, and burnout that authentic allies of disabled people can face. These gaps should be filled given that disabled people need allies and that there are many challenges for being an authentic disabled or non-disabled ally of disabled people.

Keywords: allies; ally; allyship; disabled people; people with disabilities; equity; diversity; inclusion; equality; science and technology governance; scoping review

1. Introduction

Disabled people face many problems in their lived reality as flagged by the UN Convention on the Rights of Persons with Disabilities [1] and the United Nations 2018 flagship report on disability and development: realization of the Sustainable Development
Goals by, for and with persons with disabilities [2], to just name two documents. Disabled people have been involved in activism for a long time to better their social situations [3]. Given the many challenges disabled people face in improving the social reality of disabled people, given the precarious lived reality of many disabled people [1], and given the barriers many disabled people encounter in being activists [3,4], disabled people depend on having allies (who can be so-called non-disabled people or disabled people of a different background to other disabled people) as activists to better their lived reality. However, the issue of having an ally is not simple. There is the problem of performative allyship, where the ally does not act in the ways disabled people wish [5–7], the danger of allies being gatekeepers [8,9], and that one can be an ally and an oppressor [10–15]. As authentic allyship includes being an activist, there is also the danger of activist burnout [16–25], whereby authentic allies [26–28] are in danger of “authentic allyship burnout” due to the many stressors they can experience due to their actions. Given the many challenges disabled people face in bettering their social situation and the importance of having allies, it is important to know what is known about the topic of allies of disabled people. In 2005 it was stated that “the concept of disability allies appears to be nonexistent in the literature” [29] (p. 67). However, no scoping review that looks directly at that topic exists to our knowledge. The aim of our scoping review of the academic literature was to better understand how allies and allyship are covered in relation to disabled people. To fulfill the aim of our study, we first asked using academic abstracts as sources: (1) Did the abstracts indicate that the full texts were engaging in-depth with the issue of being an ally of disabled people and especially with the challenges, stressors, and danger of burnout for allies of disabled people? We used this prescreening question to identify full-text articles that might be useful to download for analysis. For the abstracts that indicated a yes to research question 1, we then investigated the full texts asking: (2) Did the full texts cover challenges, barriers and dangers including the stressors and danger of burnout linked to being an authentic ally of disabled people? We focused on challenges, barriers, and dangers including the stressors and danger of burnout because being involved in disability activism is a long-term endeavor and as such entails the danger of activist burnout for allies. Using the abstracts only, we furthermore asked: (3) Who were identified as allies in the abstracts? Additionally, we asked: (4) What topics were mentioned in the abstracts where disabled people were seen as in need of allies? Phrases like anti-racism ally, anti-racist ally, anti-racism allyship, racial justice ally [30–37], social justice ally [38–43], and other ally phrases linked to actions that focus on changing systemic discriminations of marginalized groups, are present in the academic literature. Therefore, we investigated whether such phrases that are directly linked to disabled people are present in the academic literature and we asked: (5) Are phrases depicting ability-based systemic discriminations disabled people face, such as anti-ableism ally/allies/allyship, anti-disablism ally/allies/allyship, anti-disableist ally/allies/allyship, anti-disablist ally/allies/allyship, anti-ableist ally/allies/allyship, anti-ablist ally/allies/allyship, used in the literature?

Although different equity, diversity, and inclusion (EDI) related phrases and EDI policy frameworks are used to better the problematic situation of marginalized people, including disabled people in the workplace [44], it is noted that problems exist in how disabled people are engaged with in EDI discussions [44]. EDI could be one area of engagement for the authentic allies of disabled people and people involved in EDI could be allies to disabled people. Therefore, we asked: (6) Are there EDI phrases and frameworks covered in conjunction with ally/allies/allyship and disabled people? Finally, various science and technology governance and technology-based ethics fields emerged [45] to prevent or decrease the negative consequences of scientific and technological advancements. Disabled people need authentic allies from within the science and technology governance and technology-based ethics fields because as scientific and technological advancements impact disabled people on many levels and as new scientific and technological challenges are constantly emerging, disabled people do not have the capacity to engage with the topic all by themselves. As such, we asked: (7) Are science and technology governance phrases
and technology-based ethics fields mentioned in conjunction with ally/allies/allyship and disabled people?

1.1. Allyship and Allies

“The role of ally was popularized in the civil rights era of the 1960s with white allies in anti-racist activism, male allies in the struggle for women’s rights, and straight allies in LGBTQ (lesbian, gay, bisexual, transgender, queer) rights advocacy (Brooks & Edwards, 2009). Since the 1960s, additional allies have been identified to support the civil liberties of people with physical disabilities, serious mental illnesses, elderly, youth, transgender individuals, and other groups facing oppression. These movements have often been led by members of disadvantaged groups, with allies from advantaged groups typically positioned to offer support and resources (Iyer & Leach, 2010)” [46] (p. 18)

There are various definitions of allies and allyship [11,47–52] and various theories of ally development, such as Broido’s Model of College Student Ally Development [40], the Edwards Aspiring Social Justice Ally Development Model [42], the Bishop’s Six-Step Model to Becoming an Ally [53], the Washington and Evans’s Model for Becoming an Ally [54], the EThIC model of virtue-based allyship development [55], and the Coin Model of Privilege and Critical Allyship [56].

There is performative allyship, which is seen as a problematic form of allyship [5–7], and authentic allyship [26–28]. It is noted that there is the danger of allies being gatekeepers [8,9], that one can be an ally and oppressor [10–15,57], and that the very concept of allyship is contested [58]. Results of allyship are categorized as superficial or system-changing [59].

Many expectations are attached to allyship in general, such as that of supporting social change [12], lifelong learning [49,60], not being defined by the allyship [49], making use of one’s privilege [49,55], being aware of general privilege [12,60], giving voice to the marginalized [49,55,60–62], considering the power in language [61], understanding one’s positionality [12,61], doing research [55,61,62], and taking action [55,61–63].

1.2. Disability Allyship and Allies of Disabled People

Disability allyship is described with many of the same characteristics and some specific to the case of disabled people. Some expectations and characteristics attached to disability allyship reported are: “to promote inclusion, social change, and equity” [11] (p. 84), that one does not have to belong to the dominant group [11], that one has to understand one’s motivation [11,56,63,64], that one has to understand the term “social justice” [11], that disabled people of one group can be allies of other disability groups or other marginalized groups [11], allyship being an intentional choice [11], allyship being a constantly changing process [11], lifelong learning [11,56,63], to make use of one’s privilege [56], to be relational and structural [65], to consider the power in language [64,65], to develop a nuanced perspective on intersectional ableism and allyship [56,65], to bring internalized ableism and privilege to light [56,65], to be aware of ability privileges [66], to dismantle ableism [65], to challenge ableist practices [65], doing research [55,61,62], taking action [11,29,56,63,64], and understanding the concept of vulnerability [11]. It is also flagged that it is important to understand that disabled people are not a homogenous group, so one has to look at disabled people through what we call an intra-sectionality lens. Intra-sectionality can be based on differences between disability characteristics [11,65] but also on where one sees the disablement originating (the body, the environment, or both) [67]. As such, the allyship of a disabled person from one group to a member from another disability group could be called “intra-sectional allyship”. Intersectionality is flagged as another important aspect of allyship and the phrase “intersectional allyship” is used [65,68–70]. Indicating the importance of the intersectionality of different forms of oppression, it is argued that the systemic disablism experiences by disabled people “were exacerbated by sexism, racism, non-citizenship status, and/or fatphobia (weight shaming)” [50] (p. 8). A tool for self-
reflection for potential and existing disability allies (Disability Allyship Q-Sort) on what it means to be a disability ally, that uses 40 statements found in the literature describing disability allyship, has been generated [71] (p. 185). This thesis itself used the approach and classified the results into three types of allies, whereby the “accountable ally” was the one seen as essential by 80–90% of the participants categorized as disability studies scholars [71] (p. 66) (See Table 1). The accountable ally was seen to be an activist and to be “grounded in collaboration with persons experiencing disability or disablism” [71] (p. 67).

In 2005 it was stated that “the concept of disability allies appears to be nonexistent in the literature” [29] (p. 67). To be able to ascertain whether anything has changed since 2005, we investigated as research question 1 whether abstracts covering disability allies indicated that the full texts were engaging in-depth with the issue of being an ally of disabled people.

Many expectations are outlined for what it means to be an authentic ally of disabled people, one being that allies ought to be activists [11,29,55,56,61–64]. At the same time, it is noted that activists are in danger of activist burnout. Activist burnout, is described as:

“Activist burnout has been defined as when long-term activism-related stressors deteriorate activists’ physical or emotional health or sense of connectedness to their movements, impacting their effectiveness or abilities to remain engaged” and “Making matters worse, burnout begets burnout, as movement work is taken up by fewer people, who begin to burn out, engage less effectively, and take out their hopelessness on fellow activists” [18] (p. 364).

Allies that are activists could therefore be in danger of ally burnout due to their activist role [72]. Many stressors leading to activist burnout have been described [16,18,23,25,73] and disabled activists experience many unique stressors related to being activists that can lead to burnout [16]. Furthermore, it is argued that:

“Activist burnout theory to date has failed to account for how causes of burnout differ for people who are subject to racism, sexism, and other oppressions within movements. It also has failed to account for how the overall grind of these oppressions experienced in the everyday lives of marginalized-identity activists inside and outside their activism inform their susceptibility to burnout” [18] (p. 376).

Therefore, our scoping study investigated whether data was produced in the academic literature on the issue of barriers, challenges, and the danger of burnout faced by allies of disabled people, which includes non-disabled people being allies of disabled people and disabled people of one group being allies of disabled people of another group (research questions 2). We also investigated who were mentioned as allies (research question 3) and what topics were linked to the need for having allies (research questions 4–5).

1.3. EDI/DEI and Allies or Allyship

Many equity, diversity, and inclusion (EDI) related phrases and EDI policy frameworks are used to better the problematic situation of marginalized people, including disabled people in the workplace, including that of academia [44]. Disabled people from the PhD to faculty level experience the highest level of harassment and unfair treatment in the University workplace in Canada, according to data from Statistics Canada from 2019 [74]. Data from the USA from 2022 on the mistreatment of physicians with disabilities by coworkers and patients suggest that disabled physicians are the worst treated of the EDI-deserving groups, whereby the numbers furthermore suggest that disabled physicians are treated worse if they also belong to another marginalized group versus if one is a non-disabled physician in that marginalized group [75]. Furthermore, disabled people have low employment numbers; for example, for the USA, the employment-participation ratio for disabled people was 22.5% in September 2023 whereby the number for non-disabled people was 66% in September 2023. These two numbers shows a disparity in the employment-participation ratio of 43.5% [76]. If one looks at the numbers of disabled people in leadership positions, they are also very low. According to Statistics Canada, 0.8%
of executives are disabled males and 0.6% executives are disabled females [77]. However, these numbers are rarely used, if at all, within EDI discussions to highlight the problematic situation of disabled people. Furthermore, it is noted that many other problems exist in how disabled people are engaged with in EDI discussions, including that the benchmark targets for disabled people used and what is seen percentage-wise as disabled people, are much too low given who falls into the category of disability within EDI discussions [44]. These very problematic realities of disabled people within EDI discussions suggest not only that disabled people need more allies on this topic but also that there are specific challenges for allies of disabled people. Not only covering disabled people, the need for allyship within EDI discussions is noted for minority groups in general [78]. Allies of marginalized groups and allyship are mentioned in various EDI policy documents [78–80], as is allyship training [78]. However, it is made clear that it must be authentic allyship [26]. Various challenges for authentic allyship are noted including that “internal and external challenges demotivate potential allies such as derogated by their ingroup, experience backlash, be viewed as overly political or radical, fear of retaliation, perceived risk and questioning one’s own legitimacy in voicing support” [55] (p. 784). These factors might be even more exacerbated given the often unique EDI problems disabled people face [44] and that many disabled people experience the worst of the problem [74,75]. As such, this study investigated for our research question 6, the coverage of EDI in relation to allyship around disabled people.

1.4. Science and Technology Governance, Ethics Fields, and Allies or Allyship

Many, if not all scientific and technological advancements pose social issues for disabled people [81–91] whereby society at large and disabled people face constantly new scientific and technological advancements and changing challenges. Many science and technology governance phrases, such as “democratizing science, and technology”, “participatory technology assessment”, “technology assessment”, “parliamentary technology assessment”, “anticipatory governance”, “upstream engagement”, “responsible innovation”, “responsible research and innovation”, and “transformative vision assessment”, and ethics fields, such as AI-ethics, bioethics, computer science ethics, information technology ethics, nanoethics, neuroethics, robo-ethics and quantum ethics (many citation in [45]), have emerged to discuss how to prevent or decrease the negative consequences.

Given the many and continuous ways scientific and technological advancements impact disabled people and the knowledge needed to influence the science and technology governance discussions, disabled people need authentic allies to help cover the problems and to influence the science and technology governance discussions, given the many barriers disabled people and disability rights organizations face in their activism towards the constantly changing science and technology landscape and its governance [3].

Authentic allies could come from many areas. Authentic allies could come from within the technology-based ethics and science and technology governance area, given that the technology-based ethics and science technology governance discussions see the involvements of stakeholders as important [92–101], and given that decreasing the negative social impacts on society at large, including those on disabled people, is one focus of the science and technology governance discussions. Therefore, we asked as research question 7 whether allies/ally/allyship was covered in the science and technology governance terms and technology-based ethics fields in relation to disabled people.

In conclusion, many disabled people face many problems in their lived reality [1,2]. Disabled people have been activists with the goal of bettering their social reality for a long time [3]. At the same time many disabled people encounter barriers and challenges in being activists [3,4], including that of activist burnout [16,102], and disabled people as a social justice group depend on having allies as activists to better their lived reality as other social justice groups do. However, being an authentic ally [26–28] of disabled people (whether as a so-called non-disabled person or a disabled person being an ally for other disabled people) poses many barriers and challenges, and as authentic allies are expected to be
activists [11,29,55,56,61–64] they are in danger of experiencing activist burnout [16–25], as in “authentic allyship burnout”, due to the many stressors they can experience due to their actions. No scoping study to our knowledge looked at how allyship and allies are covered in relation to disabled people in the academic literature in general and at the issues of the barriers, challenges, and stressors of being an authentic ally of disabled people and the danger of burnout faced by allies of disabled people. Therefore, the aim of our study was to better understand the academic coverage of allyship and allies in relation to disabled people in general, and specifically the coverage of the challenges, stressors, and danger of burnout experienced by allies of disabled people.

2. Materials and Methods

2.1. Theoretical Frameworks and Lenses

We interpret our findings through various lenses and theoretical frameworks. One lens includes the expectations of allyship and allies evident in the literature. Another, the field of disability studies which investigates the lived experiences of disabled people [103,104]. And a third, the field of ability-based studies (three strands: ability expectation and ableism studies in short ability studies [105–107], studies in ableism [108–110], and critical studies of ableism [111,112]) which focuses on the investigation of ability-based expectations, judgments, norms, and conflicts to question irrelevant ability norms, “ability privileges” (having one ability opening the doors to experience other abilities [113]), and disablism, which is the systemic discrimination based on not measuring up to irrelevant ability norms [114]. It is, for example, stated: “A pernicious impact of ableism is its tendency to take-for-granted ability as a legitimate criterion for negative differential treatment, thereby making disability discrimination difficult to challenge for people with disabilities” [115] (p. 76). Ability expectations and ableism play themselves out on the intersections of different relationships, such as that of humans–humans in general, disabled humans versus so called abled humans, humans–post/transhumans, humans–cyborg humans, humans–animals, humans–nature, humans–non-sentient machines, and humans–sentient machines [105,107], all of which are relationships impacting disabled people and where disabled people need allies. Various ability-based concepts have been generated within the three strands of ability-based studies, such as internalized ableism [116], internalized disablism [117–120], ability security (when one is able to live a decent life with whatever set of abilities one has), ability identity security (to be able to be at ease with ones abilities), and ability inequity (an unjust or unfair (a) “distribution of access to and protection from abilities generated through human interventions” or (b) “judgment of abilities intrinsic to biological structures such as the human body” [107,121]), to name a few. The intersectionality of ableism and disablism with other forms of oppression is noted [122–125], as it is also noted that abilities are often used to justify negative -isms, such as racism or sexism [105,106,116, 122–127]. Dismantling ableism as in the dismantling the negative use of ability judgments) is seen as a task for disability allies [65].

Our interpretation is also guided by the political solidarity model of social change [52,128] which is conceptualized “as a construct consisting of three factors—allship with a minority outgroup, a connection to their cause, and a commitment to working with them to achieve social change—that can emerge within and across social groups” [128] (p. 726). We suggest that the measure for political solidarity [128] raises particular questions for allies of disabled people. The measure has three parts. One is allyship, with the question being whether one feels a sense of “brotherhood” or “sisterhood” with X, one feels a sense of solidarity with X, and whether one stands united with X. The second part is the “Cause Connection”, with the question being whether one has a role to play in X’s cause; and one feels connected to X’s cause. The third part is the “Social Change Commitment”, which asks whether one feels policies negatively affecting X should be changed; more people should know about how X are negatively affected by this issue; and it is important to challenge the power structures that disadvantage X [128] (p. 736, Table 4). All three parts fit with the characteristics of allies and allyship outlined in
the background section. The authors state that the measure can be easily applied to other minority groups and various social topics [128]. Indeed, the X could be filled not only with disabled people as a group but also the subgroups of disabled people, and with disabled people who perceive the origin of their disablement to be coming from different places (the body, the environment, both). As such, it can cover non-disabled allies and allyship with disabled people, but also disabled people of one group as allies of another group of disabled people. Additionally, it can cover disabled people as allies with non-disabled people, like other minority groups. Given that everyone is judged by their abilities, and that abilities are used as a tool not only to justify the negative treatment of disabled people but also other marginalized groups, the sense of brotherhood or sisterhood, to use the original wording, could also be based on being unjustly judged on one’s abilities, whether right now or in history (women were denied the right to vote, for example, because men decided that women lack the ability of rationality, or books like the Bell curve set up a hierarchy of ethnic worthiness based on cognitive abilities [105,107]). The discourse around human enhancement beyond what is species-typical sets up new ability hierarchies and is increasingly enabled through scientific and technological advancements [105,106,113,129]. The human enhancement debate is just one example that shows that ability judgments are not specific to what we label as disabled people today. As such, there could be cyborg allies of people who are not cyborgs (the new disabled people?), and people that are not cyborgs being allies for cyborgs in the future, given the cyborgization and the techno-enhancement of the human body, which raises issues of techno-ableism [87,91] and the appearance of the techno-poor disabled/techno-poor impaired [130]. Given how pervasive ability judgments and conflicts are, the disabling use of ability judgments (disablism) that disabled people experience can be looked at by others to identify for their group how they have been ability judged in history, the present, or the future.

2.2. Study Design

Scoping studies are useful in identifying the extent of research that has been conducted on a given topic and the current understanding of a given topic [131,132]. Our scoping study focuses on the extent of academic research that has been conducted on allyship and allies related to disabled people. Our study employed a modified version of the stages for a scoping review outlined by [133]. We also adhered to the PRISMA statement on scoping reviews [134]. PRISMA was set up to give a certain standard for systematic reviews and meta-analysis. Since then, PRISMA charts for other review types, such as scoping reviews, have been generated.

2.3. Identification of Research Questions

The aim of this study was to better understand the academic coverage of allyship and allies in relation to disabled people in general, and specifically the coverage of the challenges, stressors, and danger of burnout for the allies of disabled people. To fulfill this aim we first asked, using academic abstracts as sources: (1) Did abstracts indicate that the full texts were engaging in-depth with the issue of being an ally of disabled people and especially with the challenges, stressors, and danger of burnout experienced by allies of disabled people? For the abstracts that indicated a yes to research question 1, we then investigated the full texts asking: (2) Did the full texts cover challenges, barriers, and dangers including the stressors and danger of burnout linked to being an authentic ally of disabled people? Using the abstracts only, we furthermore asked: (3) Who were identified as allies in the abstracts? Additionally, we asked (4) What topics were mentioned in the abstracts where disabled people were seen in need of allies? For topics, we used as one strategy to search the academic literature (abstracts and full texts) for phrases where the very term is linked to disability rights and allies focusing on that topic. We asked: (5) Are phrases depicting the ability-based systemic discriminations that disabled people face, such as anti-ableism ally/allies/allyship, anti-disablism ally/allies/allyship, anti-disableist
ally/allies/allyship, anti-disablist ally/allies/allyship, anti-ableist ally/allies/allyship, or anti-ablist ally/allies/allyship, used in the literature?

We finally searched for two topics (science and technology governance and EDI) where we suggest disabled people need allies from the actors in relation to these topics, and whether being an ally of disabled people is mentioned within these two topics. We asked: (6) Are the EDI phrases and frameworks covered in conjunction with ally/allies/allyship and disabled people? In addition, we asked (7) Are science and technology governance phrases and technology-based ethics fields mentioned in conjunction with ally/allies/allyship and disabled people?

2.4. Data Sources, Data Collection, and Inclusion/Exclusion Criteria

On 1 July 2023, we searched the academic databases EBSCO-HOST (an umbrella database that includes over seventy other databases itself), Scopus, and Web of Science with no time restrictions. These databases were chosen because together they contain many disability studies journals, such as the “Journal of Literary and Cultural Disability Studies”, Disability & Society, Scandinavian Journal of Disability Research, Disability Studies Quarterly, “Canadian journal of disability studies”, “review of disability studies”, ALTER European journal of disability research, and non-journals such as the “Routledge Handbook of Disability Studies” and “The Disability Studies Reader”. Many other journals from many different academic disciplines covering relevant topics, such as EDI, science and technology studies, and many other topics linked to the lived reality of disabled people, were also covered by the databases. As such, the content accessible through the databases could contain relevant content to answer our research questions. As for the inclusion criteria, scholarly peer-reviewed journals were included in the EBSCO-HOST search; reviews, peer-reviewed articles, conference papers, and editorials in Scopus; and the Web of Science search was set to all document types. English language was another inclusion criteria. As for the exclusion criteria, all data found through the search strategies (Table 1) not covering content of relevance to the research questions were classified as non-relevant in the analysis.

Table 1. Search strategies used for the databases.

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<thead>
<tr>
<th>Strategy</th>
<th>Sources</th>
<th>Search Terms</th>
<th>For Research Question (RQ)</th>
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<tr>
<td>Strategy 1</td>
<td>EBSCO-HOST</td>
<td>ABS (&quot;ally&quot; OR &quot;allies&quot; OR &quot;allyship&quot;) AND ABS (&quot;deaf&quot; OR &quot;autism&quot; OR &quot;ASD&quot; OR &quot;ADHD&quot; OR &quot;neurodiver*&quot; OR &quot;palsy&quot; OR &quot;impair*&quot; OR &quot;disab*&quot;)</td>
<td>RQ 1–4</td>
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<td>Strategy 2a</td>
<td>EBSCO-HOST/Scopus/ Web of Science</td>
<td>ABS (&quot;ally&quot; OR &quot;allies&quot; OR &quot;allyship&quot;) AND ABS (&quot;Athena SWAN&quot; OR &quot;NSF ADVANCE&quot; OR &quot;See change with STEMM Equity Achievement&quot; OR &quot;Dimensions: equity, diversity and inclusion&quot; OR &quot;Science in Australia Gender Equity&quot;)</td>
<td>RQ 6</td>
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<td>Strategy 2b</td>
<td>EBSCO-HOST/Scopus/ Web of Science</td>
<td>ABS (&quot;ally&quot; OR &quot;allies&quot; OR &quot;allyship&quot;) AND ABS (&quot;Diversity, equity and inclusion&quot; OR &quot;Equity, diversity and inclusion&quot; OR &quot;Equality, diversity and inclusion&quot; OR &quot;Justice, Equity, Diversity, and Inclusion&quot; OR &quot;Diversity, equality and inclusion&quot; OR &quot;Inclusion, Diversity, Equity and Accessibility&quot; OR &quot;Diversity, Equity, Inclusion and Belonging&quot; OR &quot;Equity, Diversity, Inclusion, and Accessibility&quot; OR &quot;Equity, Diversity, Inclusion, and Decolonization&quot; OR &quot;Belonging, Dignity, and Justice&quot; OR &quot;Diversity, Dignity, and Inclusion&quot; OR &quot;Inclusion, Diversity, Equity and Accountability&quot;)</td>
<td>37 abstracts (duplicates not removed) (not downloaded; moved to strategy 2c that should find these and more (2b not in figure flow chart); RQ6</td>
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<tr>
<td>Strategy 2c</td>
<td>EBSCO-HOST/Scopus/ Web of Science</td>
<td>ABS (&quot;ally&quot; OR &quot;allies&quot; OR &quot;allyship&quot;) AND ABS (equality AND diversity AND inclusion) OR ABS (Equity AND diversity AND inclusion)</td>
<td>RQ6 (EDI terms)</td>
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Table 1. Cont.

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<tr>
<th>Strategy</th>
<th>Sources</th>
<th>Search Terms For Research Question (RQ)</th>
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<tr>
<td>Strategy 3a</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS (“ally” or “allies” or “allyship”) AND ABS (“Technology governance” OR “Science and technology governance” OR “Anticipatory governance” OR “Democratizing science and technology” OR Parliamentary technology assessment” OR “Participatory technology assessment” OR “Responsible innovation” OR “Responsible research and innovation” OR “Technology assessment” OR “Transformative vision assessment” OR “Upstream engagement” OR “AI-ethics” OR “Bioethics” OR “Computer science ethics” OR “Information technology ethics” OR “Nanoethics” OR “Neuroethics” OR “Quantum ethics” OR “Rebo-ethics”) AND ABS (“deaf*” OR “autism” OR “ASD” OR “ADHD” OR “neurodiver*” OR “palsy” OR “impair*” OR “disab*”)</td>
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<tr>
<td>Strategy 3b</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS (“ally” or “allies” or “allyship”) AND ABS (“Technology governance” OR “Science and technology governance” OR “Anticipatory governance” OR “Democratizing science and technology” OR “Participatory technology assessment” OR “Responsible innovation” OR “Responsible research and innovation” OR “Technology assessment” OR “Transformative vision assessment” OR “Upstream engagement” OR “AI-ethics” OR “Bioethics” OR “Computer science ethics” OR “Information technology ethics” OR “Nanoethics” OR “Neuroethics” OR “Quantum ethics” OR “Rebo-ethics”)</td>
</tr>
<tr>
<td>Strategy 4a</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS or full text “Anti-ableism ally” or “Anti-ableism allies” OR “anti-ableism allyship” OR “Anti ableism ally” or “Anti ableism allies” OR “anti ableism allyship”</td>
</tr>
<tr>
<td>Strategy 4b</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS or full text “Anti-disablism ally” or “Anti-disablism allies” OR “anti-disablism allyship” OR “Anti disablism ally” or “Anti disablism allies” OR “anti disablism allyship”</td>
</tr>
<tr>
<td>Strategy 4c</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS or full text “Anti- disableist ally” or “Anti- disableist allies” OR “anti- disableist allyship” OR “Anti disableist ally” or “Anti disableist allies” OR “anti disableist allyship”</td>
</tr>
<tr>
<td>Strategy 4d</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS or full text “Anti- ableist ally” or “Anti- ableist allies” OR “anti- ableist allyship” OR “Anti ableist ally” or “Anti ableist allies” OR “anti ableist allyship”</td>
</tr>
<tr>
<td>Strategy 4e</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS or Full Text “ally burnout” or “allies burnout” or “allyship burnout”</td>
</tr>
<tr>
<td>Strategy 4f</td>
<td>Scopus/EBSCO-HOST/Web of Science</td>
<td>ABS or Full Text “ally stress*” OR “allies stress*” OR “allyship stress*”</td>
</tr>
</tbody>
</table>

Given that the main disability studies journals were present in the databases, as well as many other journals that cover the lived reality of disabled people, we did not perform specific searches within singled-out journals.

2.5. Data Analysis

To answer the research questions, we performed a directed thematic analysis [135–138] of downloaded abstracts (using strategies 1, 2a and c, and 3b, and there were no relevant abstracts to download based on strategies 2b, 3a, and 4a–f). To obtain the abstracts, the citations (which also contained the abstracts) obtained through the search strategies (Table 1) were downloaded into Endnote 9 software. After using Endnote 9 software to eliminate any duplicates of abstracts, a word file was generated for the abstracts of strategy 1, another for strategies 2a and c, and 3b. The Word files were downloaded into the qualitative analysis software NVIVO 12™. As for the coding procedure, one of us coded (coloured), in NVIVO 12 sections (20 words), the sections in the abstracts that contained the terms “ally”, “allies”, or “allyship” within the Word files imported into the NVIVO 12™ software. The files with the coloured areas were then printed as PDF files, and the abstracts in these PDF files were then thematically analyzed by both authors using the comment function in Adobe Acrobat. We used Adobe Acrobat as not both authors had access to NVIVO, and we used NVIVO to highlight the ally sections in the abstracts to make it easier to focus on relevant areas.
to code the PDFs. Both authors familiarized themselves with the content of all abstracts and independently identified relevant data [137]. We then independently identified and clustered the themes based on meaning, repetition, and content relevant to the research questions [138,139].

2.6. Trustworthiness Measures

The trustworthiness measures include confirmability, credibility, dependability, and transferability [140–142]. The differences in the codes and theme suggestions of the qualitative data were few, discussed between the authors (peer debriefing), and revised as needed [141]. Confirmability is evident in the audit trail made possible by the coding functions in the NVIVO 12™ software and the comment function in Adobe Acrobat. As for transferability, the description of our method gives all the required information for others to decide whether they want to apply our keyword searches on other data sources, such as that of grey literature, other academic literature, or other languages, or whether they want to perform more in-depth.

3. Results

In the result section we show first the flow diagrams for the search strategies and the process and result of selecting the data for the quantitative and qualitative analysis Figures 1–5 and then the qualitative and quantitative data.

*Figure 1.* Flow chart of the selection of academic abstracts and full texts for qualitative analysis covering RQ 1–4.
Figure 2. Flow chart of the selection of academic abstracts covering specifically RQ 6, relating to EDI policy frameworks used in the context of being allies of disabled people, for qualitative analysis.

Figure 3. Flow chart of the selection of academic abstracts and full texts covering specifically RQ 6, relating to EDI terms and allies of disabled people, for qualitative analysis.
Figure 4. Flow chart of the selection of academic abstracts covering specifically RQ 7, relating to science and technology governance terms and allies of disabled people, for qualitative analysis.

Figure 5. Flow chart of the selection of academic abstracts covering specifically RQ 5, relating to phrases that link allies of disabled people to a specific topic or specific danger for allies, for qualitative analysis.
3.1. Quantitative and Qualitative Results

3.1.1. Disabled People and Allies and Allyship: Depth of Coverage

Of the 577 abstracts from strategy 1, 306 were false positives. One type of false positive was that the ally was from a word such as “gener-ally” where the PDF generated two words instead of one word. The second main false positive was due to the use of “impair” in ways that do not relate to disabled people.

As for the relevant 271 abstracts, the content of six abstracts indicated that the full texts focused in-depth on allies and allyship, and with that the possibility that the full texts covered challenges and dangers for allies and allyship [11,50,59,64,65,143].

Reading the full texts of the six [11,50,59,64,65,143] revealed that two mentioned burnout [11,65]. Four of the six articles mentioned challenges allies of disabled people face. In one article, the authors made use of Boyer’s “six characteristics for a community of learning: purposefulness, openness, justice, discipline, caring, and celebratory” [11] (p. 82), suggesting that the same characteristics can be used to form an “ally community” whereby such a supportive environment “reduces the danger of isolation and burnout” [11] (p. 82). Feeling obligated to be a spokesperson outside of the classroom (the author that identified as a disabled student) was identified as one cause of burnout experienced by the disabled person simply due to the sheer number of demands to educate others [65]. As for challenges faced by authentic allies, the engagement with disability as one entity and the ignoring of the differences within the group (so as not to engage with intra-sectionality) was identified as one challenge [65]. Similarly, it was noted that one disability identity does not necessarily mean one is automatically an ally for another disability group and therefore allyship has to be formed between disabled people from different disability groups [11]. Another challenge mentioned was the issue of internalizing ableism [65]. Concerning allies within the community and making the point of intra-sectional conflict, [11] cites Bell 1997, an “Internalized acceptance of the status quo among subordinate groups can also lead them to turn on members of the group who challenge it. This horizontal hostility blocks solidarity among group members and prevents organizing for change” [11] (p. 74). Another challenge for allies noted was the hierarchy among oppressed groups [11]. “Appropriation of the voice” of the oppressed [143] (p. 8) was seen as another challenge. Maconi outlined the narrative challenge for an organization being an authentic ally, whereby the narrative useful to the disabled client might decrease funding for the organization as the funding might be linked to other narratives [59].

The six relevant full texts were published in 2013, 2019, 2020 (n = 2), 2022 and 2023. As for the journals, they were published in Frontiers in Rehabilitation Sciences, Disability Studies Quarterly, Rehabilitation Psychology, Research in Social Science and Disability and Problems of Post-Communism. One was a book chapter.

All other 271 abstracts that mentioned allies in relation to disabled people did not suggest a deep engagement with allyship and allies as a concept, and we identified in these abstracts the allies mentioned and the topics of ally engagement.

3.1.2. Who Is the Ally?

We show first hit count numbers in Tables 2 and 3 and after that a more detailed narrative of the results.

Table 2. Frequency of abstracts covering different origins of allies.

<table>
<thead>
<tr>
<th>Origin of Allies</th>
<th>Number of Abstracts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not clear who they were</td>
<td>86</td>
</tr>
<tr>
<td>medical-linked people and groups</td>
<td>31</td>
</tr>
<tr>
<td>education system-linked people and groups</td>
<td>15</td>
</tr>
<tr>
<td>Technology being an ally</td>
<td>14</td>
</tr>
<tr>
<td>Family-related</td>
<td>13</td>
</tr>
</tbody>
</table>
Table 2. Cont.

<table>
<thead>
<tr>
<th>Origin of Allies</th>
<th>Number of Abstracts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabled allies</td>
<td>10</td>
</tr>
<tr>
<td>Non-disabled allies</td>
<td>10</td>
</tr>
<tr>
<td>Art-related allies</td>
<td>8</td>
</tr>
<tr>
<td>Staff</td>
<td>6</td>
</tr>
<tr>
<td>Allies from other EDI groups</td>
<td>3</td>
</tr>
<tr>
<td>Media</td>
<td>1</td>
</tr>
<tr>
<td>The IDEAD Law</td>
<td>1</td>
</tr>
<tr>
<td>Local government</td>
<td>1</td>
</tr>
<tr>
<td>Veterans</td>
<td>1</td>
</tr>
<tr>
<td>The public</td>
<td>1</td>
</tr>
<tr>
<td>The ones in power</td>
<td>1</td>
</tr>
<tr>
<td>coaches</td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Years of publication of the origin of allies abstracts.

<table>
<thead>
<tr>
<th>Years</th>
<th>Number of Abstracts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before 1990</td>
<td>0</td>
</tr>
<tr>
<td>1990–2000</td>
<td>8</td>
</tr>
<tr>
<td>2001–2005</td>
<td>7</td>
</tr>
<tr>
<td>2006–2010</td>
<td>5</td>
</tr>
<tr>
<td>2011–2015</td>
<td>14</td>
</tr>
<tr>
<td>2016</td>
<td>5</td>
</tr>
<tr>
<td>2017</td>
<td>3</td>
</tr>
<tr>
<td>2018</td>
<td>6</td>
</tr>
<tr>
<td>2019</td>
<td>10</td>
</tr>
<tr>
<td>2020</td>
<td>13</td>
</tr>
<tr>
<td>2021</td>
<td>17</td>
</tr>
<tr>
<td>2022</td>
<td>16</td>
</tr>
<tr>
<td>2023</td>
<td>8</td>
</tr>
</tbody>
</table>

As for the journals, twenty-two had disab* in the title: Disability & Society (n = 9), Disability Studies Quarterly (n = 3), The Disability Studies Reader (n = 2), Research in Social Science and Disability (n = 2), and one presence each from the Alter-European Journal of Disability Research, Intellectual and Developmental Disabilities, Disability and Rehabilitation, Journal of Applied Research in Intellectual Disability, Journal of Intellectual Disabilities, and the African Journal of Disability. Seven had the term “rehabilitation” in the title and most other journals were present once.

To give more details as to who was identified as an ally in the 271 abstracts, eighty-six abstracts mentioned allies in ways where it was not clear who exactly they were, and 76 had wordings that suggested simply people linked to the disabled people, so through their networks. 111 abstracts identified allies. The following were mentioned as allies:

The highest number of abstracts were found to cover medical-linked people and groups as allies (31 abstracts), using terms and phrases such as professionals [144–150], negative views of health professionals [151], rehabilitation professionals [152], rehab psychology [64], caregivers [153,154], social workers [155], social work misses the opportunity to be an ally [156], social work can support disabled people and their allies [157],
patients [158,159], clinicians [159–161], practitioners [162,163], physicians [164,165], occupational therapists [166,167], physiatrists [168], physiotherapists [169], adapted physical education [170], medical community [171], and medical students [172].

People one could cluster under the education system were mentioned 15 times: education system related as in academic [65,144,173–175], non-disabled researcher suspicious [176], non-disabled researcher [177,178], faculty (STEM) [179,180]), anthropology [181], student [182], student services [183], special education [184], and educators [185].

Family related allies were mentioned 13 times as in parents [147,186–189], family [145,146,190–192], friends [146,193], and siblings [195].

Disabled allies were mentioned ten times using the following terms: disabled allies [196], student with functional difference [197], newly disabled [198], non-disclosed, invisible disability [199], disability organization [200], disability groups [150], disability class members [66], centers for independent living [201], “deaf black women were their own network of allies” [202] (p. 571), and peer allies [203].

Non-disabled allies were mentioned ten times using the terms non-disabled allies [199,204–206], sighted individuals [207], hearing allies [208–211], and neurotypical allies [212].

Art-related allies were mentioned in eight abstracts: art therapists [213], artists [214–216], arts [217–219], arts teachers [220], and arts organizations [59].

The title of staff was mentioned six times, as in schools, caregivers, fitness centers, mental health staff [154,182,221–223], teachers [86,189,224,225], and sign language interpreter administrators [86].

Allies from other EDI groups were mentioned three times, as in crip/queer allies [226,227], feminism and disability studies ought to be allies [228], and disadvantaged groups [229].

Then there were allies mentioned as members of local government [230], the public [231], “the ones in power” [232], coaches [233], and veterans [150].

For when not a group or a person was mentioned as the ally, technology was mentioned 14 times as an ally [234–247], and one time as not being an ally [86]. Thee IDEA law [248], and the media [249] were also mentioned as allies.

3.1.3. Topics Identifiable in the Abstracts where Ally Was a Generic Term Used

We show first hit count numbers in Tables 4 and 5 and after that a more detailed narrative of the results.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Number of Abstracts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topics related to people covered under the terms learning intellectual disability</td>
<td>9</td>
</tr>
<tr>
<td>Disability rights and self-advocacy</td>
<td>8</td>
</tr>
<tr>
<td>Medical-related topics</td>
<td>7</td>
</tr>
<tr>
<td>Disability studies</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td>5</td>
</tr>
<tr>
<td>Services</td>
<td>4</td>
</tr>
<tr>
<td>Language</td>
<td>3</td>
</tr>
<tr>
<td>Academia</td>
<td>3</td>
</tr>
<tr>
<td>Children</td>
<td>2</td>
</tr>
<tr>
<td>Arts</td>
<td>2</td>
</tr>
<tr>
<td>Bioethics</td>
<td>2</td>
</tr>
<tr>
<td>Journalism</td>
<td>1</td>
</tr>
<tr>
<td>finding employment for autism youth</td>
<td>1</td>
</tr>
<tr>
<td>Universal design</td>
<td>1</td>
</tr>
</tbody>
</table>
For the journals, thirteen had disab* in the title: Disability & Society (n = 3), Journal of Disability Policy Studies (n = 2), Disability Studies Quarterly (n = 2), Research and Practice for Persons with Severe Disabilities (n = 2), and one text each in the Journal of Postsecondary Education and Disability, Intellectual and Developmental Disabilities, the British journal of Learning Disability, and the Journal of Applied Research in Intellectual Disability. Three journals had “rehabilitation” in the title and one “health”.

Of the 271 abstracts, only sixty-three abstracts mentioned specific topics of disability activism in need of allies.

People covered under the terms learning disability/developmental disability/intellectual disability were mentioned in nine abstracts in relation to moving into the community [250], sexual health [251], a sense of belonging [252], autonomy [253], doing research [254,255], self-directed support [256], support workers [257], and transitioning to retirement [258]. Disability rights and self-advocacy were mentioned in eight abstracts as topics in need of allies: disability rights [259], disability rights activism during war [260], global activism [261], occupying disability [262], self-advocacy high school [263], advocacy and leadership by people with intellectual disabilities [264], autism, self-advocacy organizations support [265], and advocacy within the paralympic movement [266].
Seven abstracts that covered medical-related topics included disability care [267], equity in healthcare [268], Medicaid [269], residential care [270], deinstitutionalized long-term care [271], those against institutionalization [272], and mental health [273].

Disability studies were mentioned to be in need of allies in five abstracts: “research has to work alongside disabled people, their allies, their practices, their resistances and their theorizing” [274] (p. 145), disability studies [275–277], and the future of disability research [278], as was education [279–283].

Services were mentioned in four abstracts, as in sex services [284], person-centered planning services [285], and home and community services [286], with one focusing on funding [287].

Language as a topic was mentioned in three abstracts, as in language use [288], “audism”, “dysconscious audism”, “Sign Language Peoples”, and “Deaf Gain” reflects important attempts by Deaf communities and their allies to redefine Deaf peoples, their cultures, and their languages” [241], and one stated that “Person-first language began with the community of people with intellectual disabilities and their allies in the 1970s” [289] (p. 114).

Academia-related topics were mentioned in three abstracts, as in setting up autistic-led conference [290], participatory autism research [291], and research on stigma and discrimination [292].

Two abstracts covered children, as in child benefit [293], the life of disabled children [294], artists and arts [295,296], bioethics-related as in deaf gene and embryo selection (does not cover ally in the full text by name, also abstract not in the full text) [297], and bioethics and human rights (editorial, no full text available) [298].

The other topics were journalism [299], finding employment for autistic youth [300], universal design [301], housing [302], museums [303], emergency management [304], tokenism in community development [305], service animals at workplaces [306], social support [307], gardening [308], Minecraft and socialites [309], neuroleptic abuse [310], and parenting [311].

3.1.4. EDI, Allies or Allyship, and Disabled People

In the first step we generated hits for academic abstracts engaging with allies or allyship together with EDI policy frameworks (strategy 2a). Strategy 2a generated two abstract hits for “NSF Advance” and one hit for “Athena Swan”, but none covering disabled people, so none were relevant. We then searched for EDI phrases. Thirty hits were generated for “Diversity, equity, and inclusion”, three hits each for “Equity, diversity and inclusion” and “Equality, diversity and inclusion”, and one hit for “Justice, Equity, Diversity, and Inclusion” (strategy 2b).

Given the result with strategies 2a and 2b, we moved to strategy 2c, which should also include the hits obtained with strategy 2b. Using strategy 2c generated sixty-three abstracts. Forty-five abstracts did not have content which would lead one to envision that the full texts would cover disabled people. Three abstracts mentioned disability terms but did not expand on disabled people, but the phrasing indicated that they at least were aware of disabled people within the EDI context, for example,

“that lead to inequities in the molecular imaging community and STEM as a whole. In this series coined “Visions” (Antiracism and Allyship in Action), we identify and discuss specific actionable items for improving diversity and representation in molecular imaging and ensuring inclusion of all members of the community, inclusive of race, disability, ethnicity, religion, or LGBTQ+ identity” (full text did not further engage with disabled people). [312] (p. 301)

Of the other two, one mentioned disability and underrepresented minorities [313] and one mentioned people with disabilities and being underrepresented in medicine [164].

Thirteen abstracts used terms that could cover disabled people, but it was not clear whether they thought about disabled people. So, we downloaded the full texts of these thirteen abstracts to investigate whether disabled people showed up in the full texts.
For example, the phrase “marginalized groups” was used in an abstract within: “Allyship involves members of dominant groups recognizing their privilege and engaging in actions to create inclusivity and equitable spaces for all. Individuals from dominant groups with desires to actively support others from marginalized groups are often unsure how to fight oppression and prejudice” [26] (p. 377). Reading the full text, however, revealed that it only mentioned “learn what they call their disability”, so it really did not engage with EDI and disabled people.

The phrase “marginalized group” was also used in the abstract of [314] but the full text did not further engage with disabled people.

The phrase URiM/UiM (underrepresented in medicine) was used in five abstracts [164, 315–318]. However, Powell mentioned disability, as in physicians with disability, only as part of lists a few times [164], Germino did not mention disabled people [316], Faucett mentioned disability in a list of UiM to highlight intersectionality [315], Davis we had no full text access of [317], and Owusu-Ansah did not mention disabled people but only once the term disability as an SDH indicator.

“Communities historically excluded from sciences” was used as a phrase once in [319] (p. 585), whereby the full text did not mention disabled people.

“Underrepresented minorities” was used as a phrase twice [313,320], whereby Betz did not mention disabled people in the full text [320] and Forin highlighted disability in a list of various marginalized groups and stated that data was missing [313].

“Groups who may not have been at the table previously” was another phrase used in [321], and the full text did not further engage with disabled people.

One abstract mentioned accessibility [322] but the full text did not mention disabled people.

The phrase “responsive to the needs of all its constituencies and historically marginalized groups” was mentioned once in [323], whereby the full text had a Section 3.2 on access in general where it was stated in the full text that “Access often starts with ensuring access for those with disabilities, which is a known issue in our field” [323].

Finally, one abstract contained the phrase “conventionally underrepresented or marginalized groups” [324] but the full text did not further engage with disabled people. “Patient” was listed twice as a term [325,326].

In the end, only three articles focused on disabled people to some extent [50,280,327]. As for the three that covered disabled people, in the article by Dwyer et.al. [280] the authors stated, “Most of us are members or allies of the Aggie Neurodiversity Community, a neurodivergent-led peer support community and registered student organization based at UC Davis and the article has many recommendations for making a campus accessible for neurodiverse people however, it does not deal as such with the topic of allyship or being an ally” [280] (p. 3).

Riley’s article from 2013 [327] engaged with the ASEE 2012 Exhibit Hall Diversity Booth, highlighting that this booth did not cover disabled people. Riley asked, “What would it be like if there were an organization representing engineers with disabilities on the Island? Would most able-bodied people look past or through them, or would they ask how they can be an ally?... Do disabled bodies disrupt in a different way?” [327] (p. 23.1221.7). The article then covered certain disability topics, such as disability identity, in-depth, but as to allyship it only quoted once that “Jill Humphrey makes clear in her critique of the social model of disability that the exclusion of non-disabled allies (and those with marginalized less visible disabilities such as learning or mental health disabilities) is detrimental to the disability movement because of missed opportunities for coalition building across groups (e.g., educational policies simultaneously impact poor people and disabled people)” [327] (p. 23.1221.7).

Feldner et al. stated, “addressing issues of diversity, equity, and inclusion (DEI) has become central in implementing inclusive and socially responsible rehabilitation education and clinical practice. Yet, the constructs of disability and d/Deaf identity and culture, as well as ableism and allyship are often overlooked” [50] (p. 1).
3.2. Only Quantitative Hits

3.2.1. Science and Technology Governance Terms, Technology-Based Ethics Fields, and Allies or Allyship and Disabled People

We obtained 2 hits (both with bioethics where bioethics was covered as a field of engagement for allies of disabled people, and both did not mention allies as in allies from within the bioethics field) and no hits with the other ethics field terms in our online abstract searches that contained “ally”, “allies”, or “allyship” and our disability terms (strategy 3a). As for the various science and technology concepts and ally-related terms and disability terms (also strategy 3a), no hits were obtained. Even if we removed the disability terms (strategy 3b), the online abstract search only generated twelve hits.

3.2.2. Ally Terms in a Phrase with Terms Used to Indicate Systemic Disability Discrimination and Ally Burnout or Ally Stress


4. Discussion

In 2005, it was stated that “the concept of disability allies appears to be nonexistent in the literature” [29] (p. 67). Our study suggests that the problem persists. Although the numbers of abstracts mentioning disabled people in conjunction with allies were higher since 2005, the numbers are still low. Furthermore, we found little in-depth academic engagement with the topic of allies of and allyship with disabled people which includes missing studies on the challenges, barriers, problems, and dangers, such as burnout, faced by the non-disabled allies of disabled people and the disabled allies of one disability group with disabled people of another disability group. Concepts reflecting systemic discriminations disabled people experience, such as disablism, which could be used in phrases such as “Anti-disablism allies”, were not present either. Furthermore, the list of allies and topics of activism involving allies mentioned in the abstracts suggests many gaps, such as that of allies originating from within environmental discussions, and emergency and disaster management, preparedness, and planning discussions were not mentioned to highlight only one topic. Given the topics listed, many other topics in need of being engaged with were not present. Finally, our study suggests a lack of academic engagement with the topic of allies of and allyship with disabled people within the context of discussing equity, diversity, and inclusion, science and technology governance, and ethics discussions. We discuss our problematic findings in three parts, the first part focusing on the results of the coverage of allies and allyship related to disabled people (strategy 1 and strategies 4a–f), the second part focusing on our EDI-linked results (strategies 2a–c), and the third part focusing on our science and technology governance concepts and ethics fields-linked results (strategies 3a and 3b).

4.1. Extensive Coverage of Allies or Allyship in Relation to Disabled People

The content of only six abstracts suggested that the full texts engaged extensively with what it means to be an ally around disabled people [11,50,59,64,65,143], with two covering burnout [11,65] and four [11,59,65,143] covering some challenges faced by authentic
allies. That not more studies engaged with burnout, stressors, and challenges for allies and allyship related to disabled people is a problem for several reasons. Action is one facet of authentic allyship [11,29,40,54,61,64,328,329]. As such, allies are activists and activists can experience burnout for many reasons, such as problems within and between movements, being different from the norm, unreasonable expectations, working on issues around identity, working outside the system, the persistence of sexism, racism, and other oppressions, emotional labor, the impact of one’s lived experience outside the activism that impacts the activism, and the treatment of activists in organizations [16–25]. Given the many expectations of being a non-disabled ally to disabled people and being a disabled ally to other disabled people [11,49,65], including that one has to “understand one’s own identities, take ownership of privilege, examine acts of oppression, and begin the journey of understanding others” [11] (p. 84), the allies of disabled people, whether they are disabled themselves or not, face many stressors and are in danger of burnout. Furthermore, disabled people face many specific stressors as activists [16,102,330], stressors they also face as allies of other disabled people and other marginalized groups that can lead to burnout.

There are intersectional stressors, including intersectional stigma [331] and intersectional discrimination [332,333], that add to the identity stressors activists and allies can experience. Disabled people as allies can not only experience intersectional stressors but also intra-sectional stressors, such as intra-sectional stigma and intra-sectional discrimination caused by the ability-based conflicts and judgments between groups of different ‘disability’ characteristics and different ability needs (see for example how to make a curb cut work for blind people and wheelchair users) [334–336].

Within disability studies and the three strands of ability-based studies [105–112]), many ability-based concepts have been generated to question ability-based norms and conflicts [107,116–121]. The intersectionality of ableism and disablism with other forms of oppression is noted [122–125], as is that abilities are often used to justify negative -isms, such as racism or sexism [105,106,116,122–126], as cited in [127]. Indeed, the full text of one of the abstracts that was relevant stated that it is important to understand the nuances around ableism, internalized ableism and intersectional ableism [65]. All of the ability-based concepts could be used to make people understand ability-based oppression, which could be the foundation for example in Bishop’s Six-Step Model to Becoming an Ally [53] and the Washington and Evans’s Model for Becoming an Ally [54], both of which see understanding oppression as essential. The ability-based concepts are also very useful for understanding “attitudes that exist toward individuals with disabilities and sound suggestions for transforming negative attitudes into positive ones” [29] (p. 67), to understand disability justice [66] and ability-based justice and to unmask ability-based conflicts. Ability-based conflicts and injustices exist between privileged and marginalized groups in general, as ability expectations are often used as a tool by one group to marginalize another group [105,106]. Ability-based conflicts exist also between disabled and non-disabled people, and between different disability groups, such as the literature around the hierarchies of disabilities suggests [337–344]. As such, the ability-based concepts suggest various ability-based problems that authentic allies must face that may lead to stress and burnout.

It is often stated that allies must self-reflect on their privileges and make use of their privileges [11,49,50,53,60,65,66]. The Model for Aspiring Social Justice Ally Identity Development argues, for example, that there is a danger of unacknowledged privilege [42]. Ability privilege is a term developed to specifically look at ability-based privileges [113]. With that term, for example, one can question the use of the very term “accommodation” and its othering effect which is based on ability privileges. Take the example of the washroom. A wheelchair washroom is seen to be an accommodation for the wheelchair user. However, the very washroom is an accommodation for the human body. The very building code is an accommodation for the human body. But people who use legs, and with that function in certain ways space-wise, take the washroom for granted and would not see themselves as being accommodated. However, the wheelchair user with their use of space is seen to get accommodated. There are many other ability-based concepts beyond...
ability privilege that could be used by allies to question ability-based oppression [107]. There are concepts such as disability burnout [345], as in disablism (the discriminatory use of ability expectations) burnout [16], that one can use as an ally to think about systemic discrimination and its effects. Allies could use the term racism burnout [346] if the allyship covers racial groups.

It is argued that the political solidarity model of social change [52,128] consists “of three factors—allyship with a minority outgroup, a connection to their cause, and a commitment to working with them to achieve social change—that can emerge within and across social groups” [128] (p. 726). However, the gap in the literature we found suggests a lack of data that would allow for understanding the reality and challenges to the three factors in relation to disabled people. The measure for political solidarity [128] could be employed to fill some of the gaps we found in our study. It is argued that “A key distinction between allyship and solidarity is that with allyship, socially dominant group members take action due to values or norms, rather than a sense of shared group identity with the group targeted by a perceived injustice” [347] (p. 43) citing [348]. As everyone is judged based on their abilities, and abilities are used to justify negative -isms, such as racism and sexism [105,107], one could develop an identity based on the ability judgement to broaden the group identity of the negatively ability judged. It is argued that collective action is facilitated through psychological identification with the targeted group [347]. It is argued that psychological identification can increase with the perceptions of shared experiences and inclusive identity [347] (here, the shared experience of being negatively judged on one’s abilities could be a bridge) and decrease if one sees the status quo or injustice as justified [347] (which could happen if one sees the disabling use of ability judgements as justified, such as if one sees one’s ability privilege as justified). It is noted that one can resist the “internalisation of ableism through the solidarity of disabled people and their allies” [349] (p. 365). It is noted that “acting in partnership as allies to one another within the varied iterations of ableism enhances solidarity within the disability community” [65] (p. 1). Given that many experience negative ability judgments, this could also enhance the solidarity between the negatively ability judged.

Allies ought to be knowledgeable on disability issues, the problems they face [11,54] and ought to be knowledgeable on the process [33]. However, given not only the vast differences in the lived experiences between disabled people but also the lack or bias of data on many problems, especially emerging problems disabled people face such as artificial intelligence [91,350,351], environmental issues [352–358], emergency and disaster preparedness, planning and management [359,360], and the constant appearance of new problems, for an ally to become knowledgeable is a vast task. As such, data must be generated that engages with the problems of knowledge acquisition.

Given the expectations of allies and allyship and our scoping review results, many foundational studies are needed that cover the reality on the ground for allies and the difficulties of being an ally. This study, however, also revealed two other problems: one being the topics covered and the other being who is identified as an ally.

4.2. Allies and Allyship and Disabled People: Origins of Allies and Topics of Engagement for Allies

The list of potential action topics for the allies of disabled people is vast, as are the people who are seen as allies, as indicated by our results. But our findings also show some glaringly missing topics and missing potential allies. Just to give one example, in a time of ever-increasing dangers for disabled people, linked to environmental issues such as climate change and emergencies and disasters linked to environmental issues [2], it is problematic that our search only found one abstract suggesting the topic of emergency management [304], and none at all in relation to environmental activism or disaster issues in general. Furthermore, no abstract indicated that it engaged with people involved in emergency and disaster preparedness, planning and management, or environmental activism as allies to disabled people. It is well known that disabled activists focusing on environmental issues experience activist burnout [102], face many problems within environmental move-
ments [330,352–355], and are also impacted by environmental activism [4,361]. As such, they need allies from within these areas. Emergency and disaster management planning and preparedness discussions [359,360] have many problems in how they cover disabled people. As such, allies who are situated within these discussions are also needed. Furthermore, allies to disabled people who are not from within the topic face a steep learning curve on the different aspects of how environmental changes, environmental activism, and emergency and disaster management, planning, and preparedness impact disabled people as a group, and the different groups covered under the disability label. Given that one does not obtain that knowledge through the education system [362], it is not an easy task to educate oneself on something which is seen as an essential aspect of being an ally [65]. As such, this topic of gaining the knowledge to be an effective ally needs much more attention.

Another area of topics and allies from within that topic that was missing in our data was that of science and technology governance and ethics fields that focused on the advancement of technologies such as robotics, automatization, artificial intelligence, machine learning, life sciences, and quantum technologies, to just mention some specific subsets of the technologies that increasingly impact disabled people. We engage with the science and technology angle further under Section 4.4, that is specific on this topic.

4.3. EDI and Allies or Allyship

Many different EDI-related phrases and EDI policy frameworks are used to better the problematic situation of marginalized people, including disabled people in the workplace [44]. At the same time, it is noted that problems exist in how disabled people are engaged with in EDI discussions [44]. EDI could be one area of engagement for allies of disabled people and there are by now many people involved in EDI that could be allies on EDI topics for disabled people, including disabled people of one group being allies to disabled people of another group. However, only sixty-three abstracts were found engaging with allies/allyship and EDI. Of these, only three [50,280,327] mentioned disabled people, and these three did not engage with the issues faced by allies. Our findings are problematic. There are many expectations an authentic ally of disabled people has to meet in general, but especially in relation to disabled people, such as having a good understanding of the lived reality of disabled people and how the reality of systemic disablism and the danger of disability burnout [345], as in disablism burnout (the burnout due to the systemic pervasive discrimination based on ability) [16], impacts the areas that EDI tries to address. They also have to understand the many facets of ableism [65,105–112], such as that of ability privileges [66,113], and they have to understand the intersectionality of that disability characteristic with other marginalized characteristics so they can understand intersectional allyship [65,68,363,364] and the intra-sectionality of disabled people (as in not treating disabled people as if they are one homogeneous group, something which is seen as a problem) [44,65]. There are very specific EDI issues disabled people face in relation to academia [44,365], including the bias in the research question funding landscape related to disabled people [44,365]. Allies need to be knowledgeable about all the specific EDI issues applying to disabled people to be effective, and they must be able to judge the utility of EDI policies given the lived reality of a given disabled person. There is, for example, an EDI network group on LinkedIn that has over 78,000 members, all of whom could be allies [16]. However, given our results, there is not much data that allows for a good understanding of the EDI ally of disabled people, including limited data on their literacy level on disability topics, their understanding of allyship, the problems and the danger of burnout they might face in being EDI allies of disabled people, and the issues that might prevent someone from becoming an EDI ally of disabled people. Our findings suggest a lack of data that allows for a good understanding of non-disabled EDI allies to disabled people who belong to no marginalized group, EDI allies belonging to another marginalized group (intersectional allyship), and disabled EDI allies of one disability group to disabled people of another disability group (intra-sectional allyship). One study stated for EDI professionals in general that the “lack of clear job duties, conflicting job demands, lack of
top management support, and experiences of tokenism are associated with D&I [diversity and inclusion] professionals’ experiences of burnout” [366] (p. 38). However, there is much more to it stressor-wise if one is an EDI ally of disabled people, which, for example, the 78,000 EDI professionals in one LinkedIn group face if they choose to be authentic allies of disabled people.

The Tri-agency Institutional Programs Secretariat (TIPS) (Canada) states on their webpage titled Creating an Equitable, Diverse and Inclusive Research Environment: A Best Practices Guide for Recruitment, Hiring and Retention:

“TIPS defines equity as the removal of systemic barriers and biases to enact the practice of fair and equitable treatment so that all individuals have equal access to and can benefit from the programs. To achieve this, institutions must proactively identify and address systemic barriers in their policies and work environments (e.g., racism, ableism, sexism, discrimination). They must embrace diversity, defined as differences in race, colour, place of origin, religion, immigrant and newcomer status, ethnic origin, ability, sex, sexual orientation, gender identity, gender expression, and age. Recognizing and valuing diversity and equity must be accompanied by concerted efforts to ensure the inclusion of diverse and underrepresented populations, meaning that individuals must be and feel valued, respected and equally supported” and “The institution must strive to put in place the right conditions for each individual, including those from underrepresented groups—women, racialized minorities, Indigenous Peoples, persons with disabilities and members of LGBTQ2+ (lesbian, gay, bisexual, transgender, queer, Two-Spirit, plus) communities—to reach their full potential, unimpeded by inequitable practices, including personal and systemic discrimination and racism, imposed by policies, processes and research environments. It is also important to recognize that many individuals have multiple social, economic, racial or sexual identities and often face increased discrimination or systematic barriers based on their intersecting identities” [367].

This quote outlines the massive institutional changes envisioned that need many allies, for EDI in general and for disabled people, to become a reality. But the wording, “multiple social, economic, racial or sexual identities and often face increased discrimination or systematic barriers based on their intersecting identities” [367] also indicates that there are problems in phrasing the EDI issues in relation to disabled people that pose problems for the EDI allies of disabled people. Where are the disabled people in that part of the quote? Which terms in that quote cover being a disabled person as being part of intersectional identities? One challenge for allies of disabled people noted is the hierarchy among oppressed groups [11]. One manifestation of such a hierarchy is who is visible in the EDI wordings used, which has been flagged before [44].

Academics were mentioned five times as allies in our data (strategy 1) [65,144,173–175] but not in relation to EDI. Furthermore, two abstracts (strategy 1) mentioned the suspicion of non-disabled researchers as allies of disabled people outside academia (also not EDI related) [176,177]. In one abstract (strategy 1), it was stated that “research has to work alongside disabled people, their allies, their practices, their resistances and their theorizing” [274] (p. 145). In principle, the TIPS quote suggests support for this notion. However, there are many unanswered EDI questions. What must happen for the EDI vision, as presented in the TIPS quote, to be implemented accounting for disabled people? What is the danger of burnout for a non-disabled ally of disabled people wanting to achieve that? For that matter, what is the danger of burnout for disabled people (for themselves or as allies of other disabled people) who want to make this vision a reality, given the many issues they face within the system already? What are the different barriers experienced based on different disciplines and different countries?
4.4. Science and Technology Governance Concepts, Technology-Based Ethics Fields, and Allies and Allyship in Relation to Disabled People and beyond

Technology was seen as an ally fourteen times [234–247] and not an ally once [86]. Indeed, in regard to who is mentioned as an ally in the 577 abstracts obtained from strategy 1, technology was one of the most noted as an ally. At the same time, only two abstracts (strategy 1) mentioned advancement in science and technology as an issue of ally engagement, with none indicating problems for allies. The first abstract covered deaf gene and embryo selection [297]. Reading the full text revealed that the term ally is not used anymore and that the full text described a campaign by deaf people to change certain wordings in a policy document and that many people joined them as they saw the same danger. The article noted that, although their campaign led to certain word changes, it is uncertain whether it would prevent the deselection of deaf embryos. They also stated that the issue is not over. Indeed, looking at the discussions around genetic selection on all levels, the discussions around gene editing [81,82], and what is proposed today around gene editing, the deselection and gene modification scope only became broader [368–371]. The second abstract covering bioethics and human rights was about a bioethics declaration by disabled people and their allies (the full text of the editorial was not available) [298] not indicating whether the full text would engage with the problem of being an ally.

Furthermore, scientific, and technological advancements pose many problems for disabled people if not done right. As such, it is problematic that searching abstracts for science and technology governance concepts and ethics fields linked to scientific and technological advancements generated no relevant hits together with ally, allies, or allyship in conjunction with disability terms used (strategies 3a), as disabled people need allies within the governance and ethics discussions.

Our finding is problematic for another reason. The ever-increasing appearance of new technologies poses a problem for disabled people as a whole to be up-to-date, to identify the problem, and with that what to do [3]. This problem of knowledge is also a problem for allies of disabled people not already immersed in the discussions around cutting-edge scientific and technological advancements. Very few disabled people outside of academia are in a situation where they can constantly bring themselves up to speed on the newest technology and its potential impacts on disabled people (given all the problems they already face that are not solved yet [1]), and do this in a rapid timeframe so that they can engage in anticipatory advocacy to demand being part of the anticipatory governance discussions around the impact of any given emerging technology [3], and with that, be part of setting-the-trajectory while it is still possible. Then, most academic disabled people might not be able to either, given the EDI issues they already face within academia [44,365]. As such, allies from outside the disability community are needed on these topics. People involved in the discussions covered under science and technology governance concepts and ethics fields linked to scientific and technological advancements that have emerged to prevent or decrease the potential negative consequences of scientific and technological advancements (many citations in [45]) could be allies.

4.5. Limitations

The search was limited to specific academic databases and English language literature and abstracts to answers some of the research questions. As such, the findings cannot be generalized to the whole of academic literature, non-academic literature, or non-English literature. We also did not use every disability term possible. Therefore, our findings and conclusions are based on the terms we used and are not to be generalized to every disability.

5. Conclusions, Future Research, and Implications

Our study found only 271 abstracts that mentioned allies in conjunction with disabled people, and within these 271 abstracts, only six abstracts suggested that the full texts might cover in-depth disability allies and disability allyship, whether it included non-disabled people being the allies or disabled people themselves. This suggests that many more studies
are needed that engage with the topic and that the sentiment voiced in 2005 that the “the concept of disability allies appears to be nonexistent in the literature” [29] (p. 67) still holds true. Reading these six full texts revealed that two articles mentioned burnout [11,65] and four articles mentioned challenges namely that disabled people were seen as a homogenous group [11,65], the danger of internalizing ableism [65], the hierarchy among oppressed groups [11], the “appropriation of the voice” of the oppressed [143] (p. 8), and the danger of competing narratives that are of use to the ally organization and disabled people [59]. That so few articles were covering barriers, challenges and the danger of burnout for being an ally of disabled people indicates that many more studies are needed to generate data on this topic.

Allyship was only covered in three abstracts in conjunction with EDI and disabled people. People involved in ethics and science and technology governance discussions were not mentioned as allies, although technology was the non-human entity with the most hits characterized as an ally, as were no allies mentioned from within other areas such as emergency and disaster management, preparedness and planning, and environmental discussions in general, including environmental activism. Finally, phrases that link allies and allyship to the systemic discriminations disabled people experience, such as the “anti-disablism ally”, and dangers for allies such as “allyship burnout”, were not present in the literature either. Our study has implications for various areas. Many outline the need for more research on activist burnout in general [18–20,23]. Our findings suggest that data is also needed covering people involved in authentic disability allyship and the danger of allyship burnout as allies are expected to be activists. Our findings indicate the need for many studies to be done to better understand the barriers and challenges to authentic disability allyship, the stressors experienced by authentic non-disabled and disabled allies of disabled people, and the danger of disability allyship burnout. More studies also need to be done on disability allyship within the EDI, ethics, science and technology governance, environmental activism, and emergency and disaster management, planning and preparedness contexts and the problems, barriers, and stressors they face. Furthermore, given our list of topics we recorded, one could easily identify other missing topics from the list of topics we found in our scoping review that need to be researched within the framework of allyship with disabled people.

The gaps in the data available also have educational implications. All this research needs to be done so that data can be used to generate content for education. Many allyship courses are available but given what we found data-wise on disability allyship it is doubtful that they can make use of data regarding what the reality is for disability allies. These courses can cover what a disability ally ought to do in a general sense, as for that literature exists, but our findings suggest that there is little data on the realities, challenges, problems, and dangers faced by allies of disabled people in general, and in specific topic areas. Self-assessment tools are needed that allow one to identify perceptions of allyship to potential allies and people who define themselves already as allies. There is a Disability Allyship evaluation tool using various statements reflecting different understandings of disability allyship [71]. This tool could be used more to get a feel of where people stand in relation to disability allyship. Self-assessment tools, however, are also needed that allow one to identify problems disability allies might face, the danger of disability allyship burnout on the ground, and to get a better understanding for why people decide not to become disability allies.

The lack of data and engagement with being allies of disabled people in conjunction with various topics also has implications for policy making. As policy making, including EDI policies, is supposed to be evidence-based, without the data one cannot generate policies that strengthen being an ally of disabled people and decrease the dangers of allyship burnout, barriers, and challenges to being an ally of disabled people.

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