Layers of Disability Terminology Experiences of People with Disabilities and their Relatives: An Analysis of Dutch Newspapers between 1950–2020

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ABSTRACT

Despite the current terminology debate, little is known about the terminology experiences of people with disabilities and their relatives. Therefore, their interviews and letters to editors about disability terminology experiences published in Dutch newspapers between 1950 and 2020 were examined using inductive qualitative analysis. Three themes were derived. Contributors (1) objected to the use of particular terms and explained why a change in disability terminology was required; (2) argued that a change in disability terminology was viable; and (3) opposed proposed terminological changes. Contributors stated that derogatory and outmoded terms did not accurately depict the abilities of people with disabilities, resulting in stigmatisation and exclusion. Few contributors addressed a cross-disability perspective, and there was no mention of disability policy in the terminology debate. Meaningful associations between disability terminology experiences and the visibility and onset of the disability could be established. The newspaper contributions reflected the growing self-awareness of people with disabilities and their relatives.

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INTRODUCTION

'These terms hurt and imply that we are not human'.

(board member of the Dutch Association of Little People 2007).

Disability researchers from a variety of disciplines contend that the choice of disability terminology is essential. It is believed that the use of words affects disability-related attitudes and self-perceptions (e.g., Feldman et al. 2002; Millington & Leierer 1996). Recently, disabled researchers Andrews, Powell and Ayers (2022) stated that the requirement to use person-first language disregards the diverse language preferences among people with disabilities. Peers, Spencer-Cavaliere and Eales (2014), all three having disabilities, claimed that person-first terminology is well-intentioned but overrules other perspectives on disability. The blind researcher Vaughan (2009) opposes mandatory person-first terminology for the same reason. Conway (2017), a deafblind professor and Ziss (2022), a disabled developmental paediatrician, emphasised to their students that they should respect how people choose to identify. 'We should never correct the language chosen by a patient, a family or a disabled adult advocating for the community' (Ziss 2022 115). These disability studies scholars used their unique position to challenge some linguistic aspects of the oppressive practises of the able-bodied society (Goodley 2013). An open dialogue on the culturally informed selection of disability terminology is necessary for achieving health equity, belonging and appropriate public representation (Andrews, Powell & Ayers 2022; Peers, Spencer-Cavaliere & Eales 2014). Regarding disability terminology, however, little is known about the experiences of individuals with disabilities and their relatives. As part of the dialogue about disability terminology, this article examines the voices of those who are typically excluded from political and social debates.

Disability terminology has two facets. First, language reflects public representations. The terms people employ reveal how they perceive people with disabilities (e.g., Briant, Philo & Watson 2011). Second, language influences public perceptions. The connotations and meanings of terms evoke particular representations (e.g., Feldman et al. 2002; Millington & Leierer 1996). However, over time, meanings and connotations may shift. Consequently, it is crucial to consider disability terminology at a particular time and introduce new terms when unintended representations occur (Kamenetsky & Sadowski 2020; Soffer & Argaman-Danos 2021; Zola 1993).

For a long time, organisations of people with disabilities (DPOs), disability rights activists, professionals and governments dominated the terminology debate. They have called for the use of terminology they deem appropriate and the development of corresponding guidelines (e.g., ARC 2019; Mencap 2021; NDA 2014; PWDA 2021). In the United States, activists have advocated for terms which indicate that people with disabilities face social barriers and discrimination (Fleischer & Zames 2011). This manifested itself, among other things, in the US government's adoption of new terminology with the passage of the Americans with Disabilities Act (ADA) and Rosa's Law (Ford, Acosta & Sutclijfe 2013). In the Netherlands, DPOs advocated for the use of appropriate terminology. Among others, De Graaf (1994), director of the Down Syndrome Foundation (SDS), pleaded for 'Down syndrome', Wijnbeek (1990), director of the Federation of Organisations of Parents of people with intellectual disabilities (FvO), defended the use of person-first terminology, and Krijnen and Besemer (2001) of the Council for People with Disabilities and Chronic Illnesses (CG-Raad) provided guidelines for careful word choice.

In contrast to the disability movement in the United States and the United Kingdom, Dutch DPOs did not link the terminology debate to a demand for equal rights. This is consistent with the rarity of structural or principled discussions among Dutch disability activists and the absence of long-term visions (Brants, Van Trigt & Schippers 2018). Historically, living with a disability in the Netherlands has been viewed through the lens of care and support rather than human rights (Van Trigt 2015). Under the support paradigm, compensation for limitations is a means to achieve belonging to society, rather than framing marginalisation as a human rights issue. This is reflected in the Dutch disability movement, which is primarily organised and subsidised according to impairments, diseases and syndromes, with people with disabilities as patients and consumers (Brants, Van Trigt & Schippers 2018). Although Ieder(in), the Dutch umbrella organisation for DPOs, took some steps to raise awareness of the social model, neither politicians nor individual DPOs addressed the implications of this comprehensive perspective. In contrast, activist and DPO responses are largely ad hoc and piecemeal. The disability movement in the

Netherlands does not appear to adopt an intersectional perspective (Roth 2021). By focusing on concrete issues, such as the ratification of the UNCRPD and reductions in subsidised taxicab transportation, it avoids addressing differences in the underlying structures of inequality.

The disability terminology experiences of people with disabilities have only recently been documented, with the notable exception of a 1990 inconclusive survey of people with visual impairments (Aboglo & Downing 1990). Most terminology studies concentrate on the person-first versus identity-first debate (Titchkosky 2001). The identity-first approach, as seen in the phrase 'autistic people', is preferred by people with disabilities who experience their disability as a central, defining characteristic that cannot be separated from the individual (e.g., Bury et al. 2020; Lei, Jones & Brosnan 2021; Shakes & Cashin 2019). Others who advocate a person-first approach, however, vigorously dispute this term. A person-first phrase such as 'people with epilepsy' allows them to emphasise both their shared humanity and their uniqueness (Noble et al. 2017). However, although UK and US students appeared to prefer 'person-first' terminology, they were most at ease with 'disability-implicit language', i.e., descriptions in which their disability is not explicitly mentioned (e.g., Back et al. 2016). Finlay & Lyons (2005) and Thalitaya et al. (2011) found that people with intellectual disabilities disliked the labels, although they were unaware of the precise meaning of the terms. At least partially, terminology preferences appear to be context dependent. 'Disability' is acceptable when discussing a student's academic profile, but 'additional study needs' is preferred when communicating with all students (Lister, Coughlan & Owen 2020). Similarly, some people who disapproved of autism-related terms favoured 'Asperger' (Kenny et al. 2016). This context-dependence may also explain why people with disabilities and their relatives do not always appear to have the same preferences in terminology (e.g., Kenny et al. 2016; Lei, Jones & Brosnan 2021; Noble et al. 2017).

Over time, disability terminology has evolved. Terms such as 'cripple', 'mongol', 'deafmute', 'wheelchair-bound' and 'suffering from' were once commonly used. These obsolete and pejorative terms have been replaced. Person-first terminology is gaining popularity. Despite the decline in the use of truly archaic terms, English-language journalists continue to employ medical jargon and outdated derogatory terms (e.g., Devotta, Wilton & Yiannakoulias 2013; Haller, Dorries & Rahn 2006). Also observed were changes in Swedish newspaper terminology (Lindberg & Bagga-Gupta 2021). The terminology used to describe people with intellectual disabilities in Dutch newspapers has evolved similarly to that used in English (Ter Haar, Hilberink & Schippers 2023). 'Mental handicap' replaced the now derogatory terms 'feebleminded' and 'retarded' in the 1980s. In the 1990s, the term 'intellectual handicap' took its place and the term 'handicap' has been replaced with 'disability' in the new millennium. After the year 2000, person-first terminology became widely accepted. Despite these changes, newspapers in the Netherlands continued to use outdated terminology.

Until recently, there has been scant research on individual experiences with disability terminology. For quite some time, an insider perspective on terminology as a whole has been largely absent. Two crucial aspects are missing in studies of the preferred terminology of people with disabilities. Firstly, most studies have focused on the terminology experiences and preferences of people with autism. Only recently have studies involving students begun to employ a cross-disability approach. Secondly, the focus of the studies was on person-first and identity-first preferences. Nonetheless, it is also crucial to examine experiences with terms used to describe particular disabilities.

To address this knowledge gap, our research question is: What are the disability terminology experiences of people with disabilities and their relatives as published in Dutch newspapers?

METHOD

STUDY DESIGN

This study of disability terminology experiences is a qualitative content analysis (Hsieh & Shannon 2005) of contributions published in Dutch newspaper spanning 71 years (1950–2020). The study identified, analysed and reported data-based themes using inductive thematic analysis (Terry et al. 2017). Cross-disability was pursued as the data included contributions from people with various types of disabilities and their relatives.

DATA COLLECTION

Newspaper articles from national, regional and local Dutch newspapers were collected between December 2021 and March 2022 through the online search engines of the databases Delpher and LexisNexis. Delpher [https://www.delpher.nl] is a database of digitised Dutch newspapers published before 1995. Using Optical Character Recognition (OCR), Delpher made printed newspapers searchable. LexisNexis [https://www.lexisnexis.nl] is a commercial provider of information solutions. The LexisNexis database was searched for digital newspaper articles from 1995 to 2020. Until approximately 1950, Dutch newspapers were limited in size and primarily comprised of brief news items, therefore 1950 was chosen as the starting point for the newspaper analysis.

The keywords were the Dutch terms for 'disability', 'handicap', 'cripple', 'Down', 'mongol', 'dwarf', 'lilliputian', 'feebleminded', 'moron', 'idiot', imbecile', 'deafmute', 'hearing disturbed', 'cleft lip and palate', 'harelip' and 'autism', combined with the descriptors 'language', 'term', 'word', 'name', 'label', 'description', 'insult', 'prejudice', 'stigma' and 'representation'. The chosen terms were either listed as inappropriate in Dutch terminology guidelines for correct language (e.g., De Boer 2011; Krijnen & Besemer 2001; Samuel 2021; Women Inc 2019) or as suitable alternatives.

During the search process, the titles and abstracts of all newspaper articles containing the keywords were evaluated. After downloading potentially relevant articles, the full text of each article was reviewed to determine whether it met the inclusion criteria. Due to search engine restrictions, it was not possible to simultaneously search for all keywords and their derivatives. Therefore, separate keyword searches were conducted. A newspaper article containing three distinct keywords would be discovered via three separate searches. Due to these overlaps, the total number of articles was approximated.

Included newspaper articles had to meet the following criteria: a) published in a Dutch daily newspaper between 1950 and 2020; b) publicly accessible at the time of publication; c) contain experiences with or opinions about disability terminology; and d) self-disclosure or public exposure as a person with a disability or a relative. Articles not explicitly addressing at least one disability-related term were excluded from the analysis. If neither the author of a letter to the editor nor the subject of an interview was Dutch, the article was also omitted.

People who were interviewed or who wrote editorial letters, columns or op-eds on disability terminology are referred to as Contributors. Of the contributors, the following information was gathered: relationship, social role, age group, disability type and onset of disability (Table 1).

Relationship	Person with disabilities		Relative	
	Contributor for whom a disability has been publicly acknowledged.		Contributor who identifies as a family member of a person with a disability.	
Social role	Public figure		Expert by experience	
	People with disabilities or their relatives who engage in the public sphere, such as activists or board members of DPOs.		People with disabilities or relatives without a public role.	
Age group	Adolescents	Young adults	Adults	Seniors
	Under 18	Ages 18–30	Ages 31–60	Above 60
Disability type	Autism	Intellectual disabilities	Physical disabilities	Sensory disabilities
		Down syndrome and/or intellectual disabilities	E.g., cerebral palsy, cleft lip and palate, growth restriction, or spinal cord injury	Hearing disabilities or visual disabilities
Onset of the disability	Congenital disabilities		Acquired disabilities	
	E.g., autism, cerebral palsy, cleft lip and palate, Down syndrome		E.g., spinal cord injury	

Table 1 Information gathered about newspaper article contributors.

DATA ANALYSIS

Conventional qualitative content analysis was employed (Hsieh & Shannon 2005), using inductive coding and describing phenomena for which research and theory are scarce. ATLAS.ti was employed as the analysis tool. Six analytical steps were followed to analyse the contributions (Terry et al. 2017). (1) To familiarise with the data, the first author perused the transcripts

of the 261 contributions and selected the passages that mentioned disability terminology experiences. (2) Using open coding the first author coded the relevant passages according to the contributors' experiences and preferences. When necessary, passages were divided into content units during coding. (3) The first author organised the codes iteratively using summary tables. The initial 55 codes were refined and combined into 24 codes. The definitions of these codes were supplemented with examples. (4) The first and second authors developed the final coding framework based on the preliminary codes, their interrelationships and how they indicated underlying debates regarding experienced-disability-terminology. (5) Three themes and nine sub-themes were identified by the first and second authors. (6) Following a discussion of the research methodology and findings, the three authors refined and added to the themes, subthemes and thematic maps.

ETHICAL CONSIDERATIONS

Public sources include published interviews and letters to editors. It is reasonable to consider this information public given that the purpose of these publications in public newspapers was to promote appropriate language usage (Townsend & Wallace 2016). The pseudonymised transcripts of published interviews and letters to editors do not identify specific individuals. All personally identifiable information was linked to a unique code and stored in a separate key file. The unique identifier was incorporated into the data files. In addition, translating Dutch quotations into English necessitates paraphrasing, which makes identifying personal views and circumstances challenging.

TRUSTWORTHINESS

To achieve rigorous qualitative research, we adhere to the criteria established by Morse (2015). Regarding reliability, an audit trail was kept throughout the data analysis process to document the steps and decisions made, allowing us to adhere consistently to research procedures. The research methodology and findings were discussed with five experts with disabilities. Regarding validity, data were gathered from a variety of newspapers over an extended time period. Regarding generalisability, a description of the sampling procedure was provided. In addition, the authors acknowledge their professional roles, with the first author having worked as a programme manager for multiple non-governmental disability organisations and the second and third authors teaching university-level disability studies. Although nondisabled, the first author grew up with (concealed) psychiatric issues in his family. The second author has significant functional and speech limitations due to cerebral palsy and the third author is the parent of a child with a disability.

RESULTS

CHARACTERISTICS

Newspaper articles

A keyword search of 144 newspapers yielded approximately 57,000 articles. Of these, 1,044 potentially relevant articles were identified, of which 261 (from 44 newspapers) met the inclusion criteria. There were 246 unique contributors; a contributor may appear in multiple contributions.

Contributors

Of the 246 contributors, 148 were people with a disability and 98 were relatives (Table 2). There were 184 experts by experience and 62 public figures. In 26 instances, the disability was acquired, while in 138 instances it was congenital. Most contributors were adults (n = 79). Men with disabilities and female relatives were the most active in sharing their experiences. People with disabilities were interviewed more frequently than their relatives (n = 99 and n = 50, respectively (Table 2)).

National newspapers published 105 contributions. There were 140 contributions in regional newspapers and 20 in local papers. Four articles were published in both national and regional newspapers. Contributions may consist of interviews or opinion pieces. Interviews are articles in which a reporter cites or quotes a contributor. Contributor-written letters to the editor, op-eds and

		PEOPLE WITH DISABILITIES (N = 148; 60%)		RELATIVES (N = 98; 40%)		TOTAL
		EXPERTS BY EXPERIENCE	PUBLIC FIGURES	EXPERTS BY EXPERIENCE	PUBLIC FIGURES	
	Total	107 (43%)	41 (17%)	77 (31%)	21 (9%)	246 (100%)
Gender	Female	43 (40%)	11 (27%)	47 (61%)	10 (48%)	111 (45%)
	Male	51 (48%)	28 (68%)	17 (22%)	11 (52%)	107 (43%)
	Undisclosed	13 (12%)	2 (5%)	13 (17%)	0 (0%)	28 (11%)
Age group	Adolescents (under 18)	12 (11%)	1 (2%)	2 (3%)	0 (0%)	15 (6%)
	Young adults (ages 18–30)[1]	22 (20%)	2 (5%)	1 (1%)	0 (0%)	25 (10%)
	Adults (ages 31–60)[1]	28 (26%)	26 (63%)	13 (17%)	13 (62%)	80 (32%)
	Seniors (above 60)	6 (6%)	3 (7%)	10 (13%)	0 (0%)	19 (8%)
	Unknown	40 (37%)	9 (22%)	51 (66%)	8 (38%)	108 (44%)
Disability type	Autism[2]	10 (9%)	4 (10%)	9 (11%)	4 (17%)	27 (11%)
	Intellectual disability/ Down syndrome[2]	16 (15%)	0 (0%)	50 (63%)	13 (57%)	79 (31%)
	Physical disability	57 (53%)	29 (71%)	6 (8%)	3 (13%)	95 (38%)
	Sensory disability	24 (22%)	8 (20%)	14 (18%)	3 (13%)	49 (20%)
Onset	Acquired disability	15 (14%)	4 (10%)	6 (8%)	0 (0%)	26 (11%)
	Congenital disability	55 (51%)	20 (29%)	53 (69%)	12 (57%)	138 (56%)
	Unknown	37 (35%)	17 (41%)	18 (23%)	9 (43%)	82 (33%)
Contribution	Interview[3]	72 (66%)	27 (66%)	27 (35%)	13 (57%)	139 (55%)
	Opinion piece[3]	37 (34%)	14 (34%)	51 (65%)	10 (43%)	112 (45%)

Table 2 Contributors' backgrounds and roles.

[1] One contributor was of unknown age in one contribution and an adult in a later contribution.

[2] Two contributors were relatives of a person with autism and intellectual disability.

[3] Several contributions have multiple contributors. Some of the contributors are both authors and interviewees.

columns constitute opinion pieces. The majority of interviews appeared in regional newspapers (n = 83), while the majority of opinion pieces appeared in national newspapers (n = 58).

The number of contributors was highest between 2001–2010. The earliest contribution was published in 1959 and the most recent in 2020. The peak number of contributors discussing restricted growth terminology occurred between 1971 and 1980. After 1991, the number of contributors discussing intellectual disability and Down syndrome terminology increased, with a peak between 2001 and 2010. After the year 2000, increasingly more contributors discussed autism-related terms, reaching a peak after 2011. At the beginning of each peak, a relatively small number of contributors contributed multiple times, followed by a larger number of contributors contributing fewer times.

In this study, we examine the terminology experiences of people with disabilities and their relatives, as expressed in newspapers. The following section elaborates on the nature of the themes and subthemes associated with different types of arguments in the terminology debate, as well as the relationship between themes and specific contributor groups.

THEMES IN THE TERMINOLOGY DEBATE

In general, the terminology-related contributions were straightforward. In a multitude of brief statements, a few alternating and recurrent arguments were used: 'I find the use of this particular term annoying because…' or 'It is preferable to use another word because…' The pros and cons of the employed terminology were not thoroughly discussed. Experiences were only mentioned briefly.

Three themes were derived from the data. These themes relate to different types of arguments in the terminology debate: 1) terminology objections; 2) constructive comments; and 3) resistance.

Terminology objections

Objection to terminology used was the main theme. Most contributors cited these experiences as the primary argument for avoiding the disputed terminology. Five interconnected subthemes comprised this theme: (A) emotions, (B) sensing ignorance of terms, (C) feeling mocked, (D) sensing ignorance of capacities and (E) feeling excluded. The contributors interconnected the five subthemes to one another in a variety of ways (Figure 1).
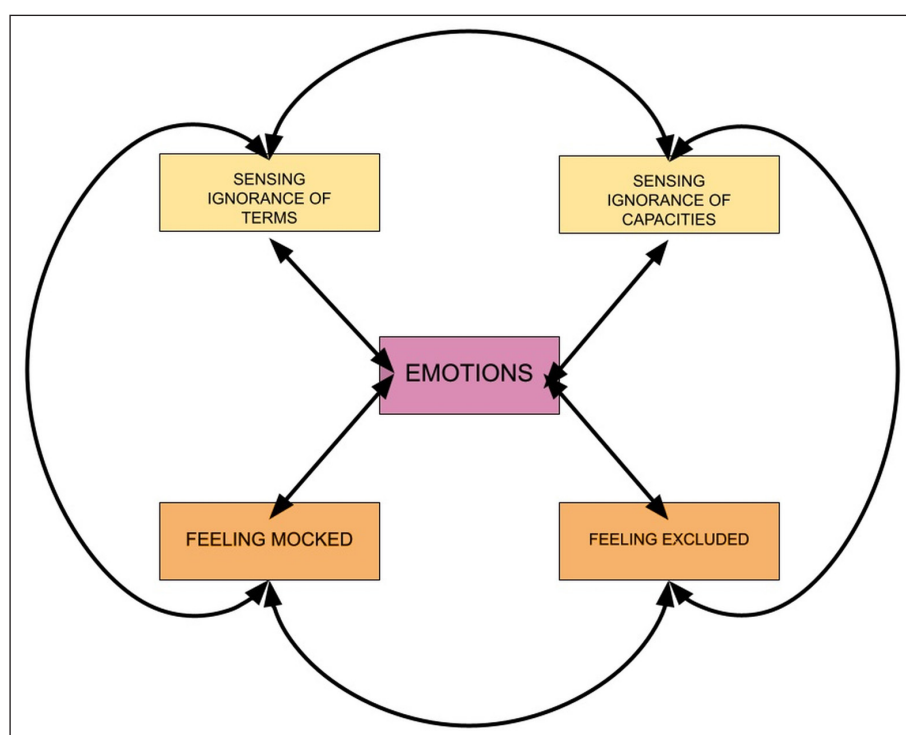

Figure 1 Theme Terminology objections.

Emotions: 'We were shocked to hear that phrase used again'
Many contributors mentioned the overarching subtheme of Emotions, frequently in relation to the other subthemes. The Emotions subtheme was dominated by a strong sense of hurt and annoyance. The contributors explained that the use of particular terms causes people with disabilities to feel harmed, shocked or disappointed. The terminology employed was considered insensitive, derogatory and hurtful. Contributors highlighted their personal emotional reactions by using short phrases such as 'what a shame', 'feels derogatory', 'negative sound', 'horrible term' and 'ugly word'. Additionally, it was stated that other people with the same disability would react similarly to these terms. Adolescents utilised this subtheme the most.

Contributors with all types of disabilities reported feeling hurt or annoyed by terminology, particularly those with congenital disabilities. However, few contributors with autism used emotional arguments.

The subtheme of emotions can be summed up as follows: Be considerate of our emotions and refrain from using these terms. This subtheme is illustrated by an excerpt from a letter to the editor written by an activist with a physical disability in 2018:

> 'Many people with disabilities experience sadness when hearing the term "invalids." Please guarantee that you will not use the word "invalid" in future articles.'

Sensing ignorance of terms: 'They have no idea what it means'
Some contributors complained about the way terms are employed. They attributed the use of wrong, outdated or derogatory terms to an alleged ignorance of disability terminology. It was argued that users were unfamiliar with the meaning of words or did not consider the acquired negative connotations. Therefore, definitions and connotations of the terms and reasons for preferring an alternative term were discussed. Primarily, background information on idiomatic expressions was presented. Particularly, public figures used this argument and especially adults and seniors acknowledged that certain terms had become outdated. Adolescents and young adults mentioned the incorrect use of terms.

Contributors with all types of disabilities mentioned ignorance of terms. Outmoded terminology in relation to intellectual disabilities and hearing impairments was particularly criticised. People with congenital disabilities and their relatives were more likely to comment on experienced terminology ignorance than people with acquired disabilities.

The subtheme of ignorance of disability terminology is summed up by the phrase: Please use more precise language and consider the meaning of terms before employing them. In 2013, an adolescent with a physical disability recounted her life story in class:

> 'The term "handicap" is stupid and unnecessary, in my opinion. Since everyone has limitations in the end, let's simply refer to it as a disability.'

Feeling mocked: 'They use our disability as a curse word'
The experience of deliberately offensive disability terminology was the third subtheme. Some contributors observed that certain disability-related terms were used as curse words or to make fun of others, in particular terms with negative connotations. The children taunt each other with, 'You stupid mongol', a mother complained in an interview. Contributors with restricted growth frequently expressed their displeasure with words such as 'midget', 'gnome' and 'dwarf': 'These are fairy tale characters.' Adolescents and senior relatives mention the mocking aspect of disability terminology the most.

Specifically, contributors with visible disabilities such as Down syndrome, cleft lip and palate and restricted growth reported mocking experiences. Only contributors with sensory disabilities mentioned no mockery. Contributors with congenital disabilities were more likely to comment on mockery than those with acquired disabilities.

The subtheme of feeling mocked conveys the message that disability terms are not intended to be used to curse or mock others. An adolescent with cerebral palsy discussed her experiences in a 1970 interview:

> 'On the one hand, many people view kids like ours as pitiful, but when we're not around and unable to respond, they make fun of us and use our disability as a curse word.'

Sensing ignorance of capacities: 'They assume we have a severe disability'
The fourth subtheme was established by the misconceptions expressed regarding the capacities of people with disabilities. Many contributors complained that the terms did not adequately describe the person with a disability, thereby frequently referring to the presumed inabilities of that person. The terms people employed revealed their ignorance and prejudices. Inadvertently, the terminology employed implied that people with disabilities are less talented. Therefore, contributors provided information about the disability itself and contrasted the alleged lack of abilities with the specific abilities of people with this type of disability. Moreover, according to contributors, different types of disabilities were sometimes confused for one another, leading to the incorrect attribution of presumed inabilities to people with a particular type of disability. All disability groups mentioned disability ignorance in their contributions, but adult contributors did so slightly more frequently.

Arguments and preferred terminology were directly connected to the contributor's disability. People with restricted growth explained, 'We are normal people with the disadvantage of being shorter than others'. And because epileptic seizures do not necessarily involve falling, but rather absences, epilepsy should not be called a 'falling disease'. The argument of capacity ignorance was most frequently used by contributors with hearing disabilities or autism, with contributors with hearing disabilities emphasising their abilities and contributors with autism emphasising

that they are people first ('Autism is a part of who I am, but I am more than that'). Contributors with acquired disabilities were more likely than those with congenital disabilities to note that certain terms may result in underrated capacities.

The subtheme of inadequate knowledge of capacities argues that appropriate terminology must be used to dispel prevalent myths about the capacities of people with disabilities. This is demonstrated by a letter written by a father in 1991:

> 'While reading your newspaper on [date], the article "Deaf and dumb abused" grabbed my attention. What a shame that today's newspapers still use the term "deaf and dumb". It's a term that's completely out of date and out of context. An individual who is deaf is far from being stupid. This is also obvious in your article: this young man appeared to be able to speak effectively with the assistance of an interpreter. People who are deaf can keep up in today's world thanks to the modern educational techniques and tools available to them. As a result, a deaf person's educational level is far greater than that of a "dumb" person and they are excellent communicators.'

After 1990, an increasing number of contributors emphasised the significance of person-first language.

Feeling excluded: 'This word fosters discrimination'.
The fifth subtheme addressed complaints regarding terms that exclude and limit participation. A few of the contributors brought up this argument. They rejected this terminology because it stigmatises. The application of these terms would perpetuate outdated representations. 'Language is, in a sense, the mirror of society', wrote the father of a child with an intellectual disability to a newspaper. Contributors noted that they experienced themselves to be portrayed as 'the other', as abnormal or as inferior, resulting in feelings of exclusion, alienation and not belonging. A man with a hearing disability wrote: 'Many consider a person labelled "deafmute" to be the lowest of the low. This word is stigmatising'. More adult contributors than any other group mentioned the risk that terminology could lead to exclusion.

The term 'mongol' was specifically mentioned in relation to exclusion.

The subtheme of experienced exclusion emphasises that people with disabilities desire belonging as much as anyone else. Therefore, inclusive terminology should be employed. In an interview conducted in 2005, a public figure with a disability stated:

> 'We must stop using the term "handicapped" and our public representation needs to be polished. We are valuable individuals and by no means a segregated group.'

Constructive comments

Together, the positive illustrative comments of some contributors with disabilities that support the need for a change in terminology formed a distinct theme. Three subthemes were identified within these additional comments: (A) viable, (B) understandable and (C) wordplay. These subthemes were not interconnected (Figure 2). Although all contributors utilised these constructive comments, adult public figures utilised them the most.
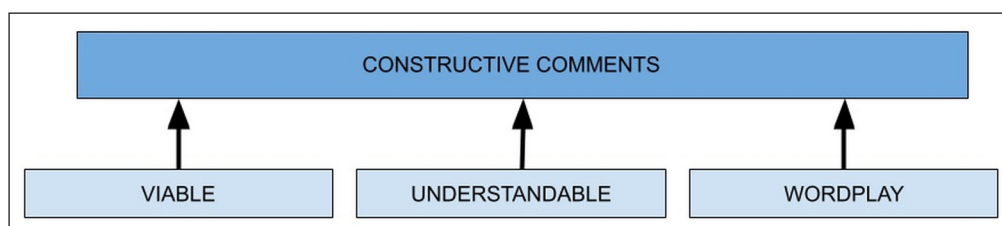
Most frequently, constructive comments were used when discussing congenital disabilities.

Viable: 'The Netherlands can also adopt this term'.
The first subtheme consisted of remarks that demonstrated the viability of modifying disability terminology. A few contributors emphasised that there is no justification for continuing to employ

outdated and improper terminology given the availability of suitable alternatives. Instead of mentioning their own experiences, they referenced experts who provide viable solutions. A father and DPO board member wrote, 'The correct term is "schisis" or "lip, jaw and/or palate cleft". I cannot envision an oral surgeon using the term "harelip"'. Other languages' correct terminology was also provided, such as 'hearingless' as a suitable alternative to 'deafmute' in German. In addition, it was demonstrated that the use of similar terms to describe other disabilities, people of colour or races would have unacceptable stigmatising effects. Several relatives stated that the improper use of the term 'mongol' is comparable to the use of the 'N' word in place of 'people of colour'. Most frequently, public figures used the viability argument.

Contributors specifically raised the viability of terminological shifts regarding 'Down syndrome'.

An illustration of the viability subtheme in a 2009 letter from a mother:

> 'Refer to it as "deafness" or "hearing disability" as physicians would. Your editor's statement in the [date] article that "we shouldn't make such a fuss and that there is no good substitute for this word" is extremely short-sighted'.

Understandable: 'They mean no harm in saying it'
The contributions indicating that it is understandable to use outdated or negative terminology, unintentionally or unconsciously, formed a second subtheme. A handful of contributors explained that they understood why individuals did not always use the appropriate terminology. While clarifying the rejection of the term 'invalid' in favour of 'people with disabilities', an activist with a physical disability wrote, 'As long as they are commonly referred to as "people with a handicap" or "the handicapped", that's fine with me'. Contributors also argued that permitting insiders to use terms that outsiders are not permitted to use can be deceptive. '"Spastic" is a word I am allowed to use because I am disabled, but others are not'.

In 2005, a father wrote an op-ed in which he explained why the use of inappropriate language is sometimes understandable: 'Because I have never forgotten how naive I once was, I am not offended when someone uses "mongols" instead of "children with Down syndrome"'.

Wordplay
The third subtheme consisted of examples of wordplay. A few contributors used language puns to lighten their serious messages or to sign off their letters with a wink.

Wordplay in a letter from a person with hearing disabilities (1991):

> 'We are not "disturbed", but we know what disturbs us'.

Resistance

Midway through the 1990s, resistance to terminology innovations emerged as a new theme, albeit one that was employed by few contributors. Previously, most contributors advocated for new terms and rejected the older ones because of their negative connotations.

Adult relatives, in particular, expressed their displeasure with the innovative views on people with disabilities behind the new terminology. They opposed the care and support innovations represented by the new terms, such as inclusion and small-scale community services. Nonetheless, the contributors employed the same themes in the terminology debate (Figure 3). They argued that the new terms were euphemisms that obscured rather than illuminated (theme 'sensing ignorance of terms'). One father stated in an interview, 'Name the subject: the deaf, the
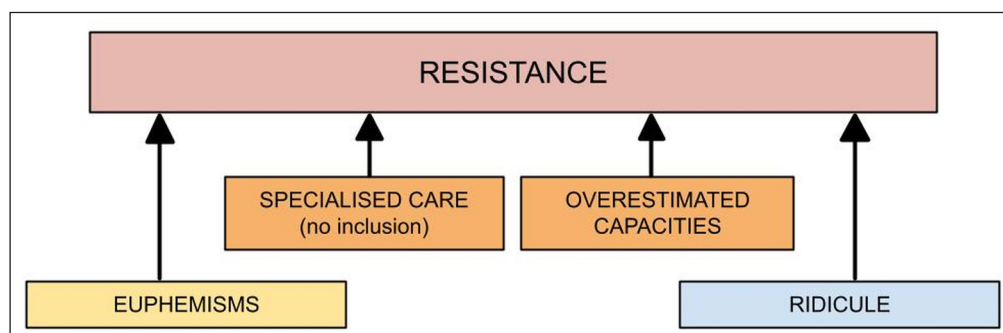
Figure 3 Theme Resistance.

blind, the invalids'. Adult relatives also asserted that, to obtain specialised care outside of society (subtheme 'feeling excluded'), it is necessary to emphasise the limitations and vulnerabilities of people with disabilities (subtheme 'sensing ignorance of terms'). The tone they used in the debate shifted from humour to ridicule (subtheme 'wordplay').

The greatest opposition was directed at revisions to the terminology for intellectual disabilities.

The resistance subtheme can be summed up as follows: we oppose terms that represent shifting perspectives and policies. In a 2002 op-ed, the sister of a woman with an intellectual disability wrote cynically:

> 'People like her are now referred to as "people with capacities". A magnificent phrase.
> They advanced from backward to retarded, from retarded to intellectually disabled
> and are now bursting with potential! They were transferred from the madhouse to an
> asylum, then to an institution and finally to the in-patient care unit. They progressed
> from fools to patients, pupils, residents and now clients. You would be jealous of them'.

CONCLUSION AND DISCUSSION

The aim of this study was to learn more about the disability terminology experiences of people with disabilities and their relatives. The analysis of letters to the editor and interviews revealed different layers in terminology-experiences. Contributors addressed disability terminology in three ways. They (1) objected to the use of particular terms and explained why a terminology change is necessary; (2) argued that a change in terminology is viable; and (3) opposed the proposed terminological changes.

Prior research has demonstrated that people with disabilities, especially students and people with autism, have complex preferences regarding disability terminology. The present research reveals that multiple terminology-experience layers underpin these preferences. The relationship between these experiences and the changing position of people with disabilities in the Netherlands, both across disabilities and over time, will be discussed in the next section.

DISCUSSION

Contributors to this study argued that derogatory and outmoded terms do not accurately depict the capacities of individuals with disabilities. This results in curse words, stigmatisation and marginalisation. They claimed that using appropriate terminology could mean the difference between belonging and exclusion. However, the contributors only challenged the negative connotations of certain terms rather than questioning the systemic injustice due to labelling. While activists elsewhere use terminology in their fight for equal rights and participation (e.g., Fleischer & Zames 2011; Ford, Acosta & Sutclijfe 2013; Oliver 1996; Zola 1993), the vast majority of Dutch contributors did not mention political or social transformations. No connections were made between the terminology debate and the politics of disability. Few contributors mentioned societal barriers, and terms such as 'public representation', 'stigma' and 'prejudice' were rarely used. This is consistent with the lack of principled discourse within the Dutch disability movement (Brants, Van Trigt & Schippers 2018).

Disability terminology experiences appeared to remain stable over time in this study that spanned more than seven decades. However, two time-related aspects stood out: (1) terminology contributors focused on different types of disabilities at distinct times and (2) the 1990s witnessed two thematic shifts. Due to their design, previous terminology studies were incapable of detecting changes over time (e.g., Back et al. 2016; Bury et al. 2020; Kenny et al. 2016; Lei, Jones & Brosna 2021; Lister, Coughlan & Owen 2020). The appropriation of specific terminology is associated with self-awareness, empowerment and group formation. Martin (1991) and Smith (1992) demonstrated that increasing emancipation and group identity frequently coincide with a claim to terminology for people of colour, whereas Brontsema (2004) demonstrated the need for changing terminology to affirm the evolution of LGBTQ+ identities. The shifting emphasis on various types of disability might reflect the varying timeframes for empowerment of people with specific disabilities in the Netherlands. For example, the number of specific contributors peaked after the founding of the Association of Little People (BKM) in 1974, the Down Syndrome Foundation (SDS) in 1988, the LFB association of people with

intellectual disabilities in 1995 and the gaining momentum of the movement of concerned parents of people with intellectual disabilities in the 1990s. Two thematic shifts appear to reflect the increased self-awareness of people with disabilities and their relatives in the 1990s. The first thematic shift was constituted of contributors emphasising the use of person-first language. This coincided with a rise in newspapers' use of person-first terminology (Ter Haar, Hilberink & Schippers 2023). These contributors preferred to be referred to as people first, their disability being just one of many defining characteristics. The second thematic shift was observed in the resistance theme. Opponents of the proposed changes desired terminology that accurately reflects the severity of disabilities to guarantee access to care and support. Both shifts represent the then-prevalent individualistic perspective on citizenship, when Dutch policies became more individualistic and neoliberal, with austerity on the one hand and equal rights and responsibilities for people with disabilities on the other (Brants, Van Trigt & Schippers 2018).

Disability terminology experiences appeared to be (partly) dependent on demographics (i.e., age), social roles (i.e., being a public figure) and aspects related to the disability (i.e., onset and visibility). For instance, adults complained about outdated terminology, adolescents acknowledged to being mocked and public figures were more likely to use constructive comments than experts with experience. Nonetheless, it is notable that most contributors focused on their own type of disability (or that of their relative) and did not discuss an overarching cross-disability perspective. This primarily own-group strategy appears to imply the absence of shared disability identities (cf. Gill & Cross 2010; Gilson, Tusler & Gill 1997; Shakespeare 1996; Valeras 2010). This is in line with the Dutch disability movement, which is organised predominantly by impairments (Brants, Van Trigt & Schippers 2018) and not by intersectional common goals. Nevertheless, contributors with different disabilities described similar disability terminology experiences. Recent cross-disability activist initiatives, such as 'Coalition for Inclusion' [Coalitie voor Inclusie], 'We're Up!' [Wij Staan Op!] and 'Back to the woods' [Terug naar de bossen] (Brants, Van Trigt & Schippers 2018), have yet to yield cross-disability terminology contributions, however.

LIMITATIONS

This analysis covered newspaper contributions from 1950 until 2020. Contributors were people with a variety of disabilities and their relatives, with various roles within the disability community. Nevertheless, the 261 newspaper contributions spanning seven decades may illustrate the problem of the (under)representation of people with disabilities in the media. This suggests that persons with disabilities were hampered from participating in the public debate on public representation. Subsequently, this study probably lacks diversity among its contributors, excluding the voices of those who were unable to participate in this debate or chose not to disclose their disability. The second limitation is the limited scope of the examined media. Not included were mainstream sources such as periodicals, radio, television and social media posts about disability terminology (cf. Shakes & Cashin 2019; Thoreau 2006).

FURTHER RESEARCH

As DPOs, activists, experts and governments have previously dominated the terminology debate, this study included the terminological comments of experts with experience. Several factors (demographics, social roles and disability-related aspects) appeared to be associated with differences in disability terminology experiences. Additional research is needed on how people with disabilities experience public representation. For example, how the intersection of the aforementioned factors, such as gender, role and ethnicity may influence these experiences and whether these experiences relate to public representation from a medical perspective as opposed to a more human rights perspective, as noted by Van Trigt (2015).

CONCLUSIONS

Disability terminology experiences of people with disabilities highlight the influence language has on their lives. In their newspaper contributions, people with disabilities and their relatives stated that it is inappropriate to use derogatory and outdated terminology. Two reasons are given for feeling hurt or annoyed when inappropriate terms are used. Contributors felt insulted or mocked with these terms and they feared exclusion when terms referring to limited

capacities or inferiority are employed. Factors such as age, social role and disability-related aspects were associated with these terminology experiences. Since DPOs and activists have dominated the terminology debate for a long time, it is important to note that, despite using different arguments, public figures and experts by experience did not have different terminology preferences.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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