DIALOGICAL SENSE-MAKING IN THE DIGITAL PUBLIC SPHERE: 
CITIZENSHIP, CARE, AND DISABILITY

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ABSTRACT

This article explores the contested public discourses of citizenship and care surrounding national media coverage of the news story of ‘Baby Leo’, a New Zealand baby born overseas in 2015. Baby Leo’s diagnosis of Down Syndrome soon after his birth, precipitated the mother’s alleged abandonment of the child, the expat New Zealand father then fundraising for the child’s (and his) rapid return to New Zealand via a virally successfully crowdfunding campaign. The situation attracted significant media attention for several months, with thousands of New Zealanders providing comments, via Facebook, on stories produced and shared by news media outlets. We use a Bakhtinian dialogical analysis of a selection of these Facebook comments to consider the emergent discourses of citizenship – especially in relation to disability – that were mobilised and contested by contributors. Our findings show that although the Facebook comments demonstrate the contingent and fluid meanings of ‘home’ and ‘welcome’, the positive comments on the worthiness of his case and its deservingness of public support that Baby Leo attracted, distinguish this case from other studies of citizenship attribution for people with Down syndrome around the world. Despite this, the treatment of prospective citizens with various forms of disability issues (including Down Syndrome) seeking citizenship in New Zealand remains exclusionary and the New Zealand national identity invoked in these online discussions extended a longstanding utopian humanitarian vision, without critical awareness of this.

Keywords: Bakhtin; dialogics; disability; Down syndrome; New Zealand

INTRODUCTION

On 21st January, 2015, Leo Forrest was born in Armenia, to an Armenian mother and a New Zealand expat father. Shortly after his birth, baby Leo was unex-
pectedly diagnosed with Down Syndrome. A few days later, his father, Samuel Forrest set up a ‘GoFundMe’ crowdfunding page to support his return to, and care in, New Zealand, due to the alleged circumstances of Leo’s mother, Ruzan Forrest, abandoning Leo after his diagnosis. The campaign took off quickly, leading in turn to a flurry of global media attention, and for a few weeks, ‘tiny Leo Forrest was the most talked about child in the world’ (3 News 2016). In New Zealand, the story was covered by several major print and television outlets, who posted links to these stories on their respective (public) social media pages, where thousands of people left emotive comments. While the initial media coverage was concerned with the viral success of the crowdfunding campaign – which raised over $500,000 from nearly 18,000 different donors around the world (Taylor 2016) – the story maintained a presence in the media cycle for over a year, during which time the focus shifted onto Samuel Forrest’s parenting background, the subsequent reuniting of Ruzan with Leo and Samuel a month after Leo’s birth, and the family’s move back to New Zealand. Controversy also emerged at this later point over the use of the donated funds, and the later alleged assault of a trustee for this money.

In this article we use a dialogical analysis of Facebook comments on the early period of this media coverage, to consider the emergent discourses of citizenship – especially in relation to disability – that were mobilised and contested by contributors. Such issues remain of contemporary importance in Aotearoa New Zealand when families with children with intellectual disabilities (including Down Syndrome) have been turned away from residency or citizenship on this basis (White 2020). We argue that the experiences of potential citizens with Down syndrome and their commentators reveal ‘a continuum from “thin” citizenship as a passive status based upon legal rights, to “thick” citizenship, where the active citizen belongs and participates in and with their communities and has rights and obligations towards multiple groups or communities’ (Blanch 2020, 37–38). As part of this we show the role of Facebook in facilitating not only reflection and discourse about these rights and obligations, but a space for invoking and enacting citizenship through speech acts.

ETHNOGRAPHY AND BAKHTINIAN DISCOURSE

Anthropologists offer a unique lens on digital communities (Walker 2010) which intersect with the local and the global, both in the structure of online social networks, and the circulation of social discourse. Even so, an analysis of Facebook comments on news media pages covering the Baby Leo stories might (due to their triteness and brevity) appear to be too one dimensional for an ethnographic analysis. The noticeable ‘conversational’ form of content
on these pages, as networked public spaces, however suggested that a dialogical analysis based on the work of early 20th century Russian philologist and a literary analyst, Michael Bakhtin, could be appropriate. Bakhtin’s work provided a new dialogical theorisation of the novel and also produced a distinctive concept of language which emphasised its fragility, historical specificity and ‘heteroglossia’ (the proliferation of internal differentiation and stratification of language and worldviews) (Bakhtin 1981, location 1039–1305 of 6377). There are strong parallels with his view of language, and the dialogical interface of Facebook posts. For example, when Facebook comments are turned on, media outlets’ public-facing social media pages allow for a variety of voices to appear in comment upon the more tightly stylised content of the original newspaper article. These comments establish a conversation between multiple parties, that is linked into the concerns of contemporary society and yet often criticises and complicates the original newspaper storyline. In this way Facebook pages operate in a more carnivalesque mode of news reporting – the framework of the carnivalesque being one of Bakhtin’s most significant scholarly contributions – for while the media outlets’ print and broadcast content and official webpages police the purity of the news narrative, the social media pages presenting the same stories allow for public participation through humour, conflict, parody and grotesque claims – acting, in other words, as ‘the speech life of peoples’ (Bakhtin 1981, location 1305 of 6377).

Such ideas lie close to the interests of ethnographers in the ‘ongoing process of social interaction and struggle’ that is part of all human societies and cultures (Cimini 2010, 399). Yet only a few contemporary ethnographic researchers have embraced Bakhtinian theories, or dialogical techniques (Tedlock 1987). This is despite the alignment of the technique with contemporary poststructuralist schools of anthropological inquiry, via the way that ‘Bakhtin’s concept of dialogue points to a situation of competing claims to truth and authority as the condition in terms of which all human interaction takes place’ (Garriot & O’Neill 2008, 382). Cimini’s (2010) work is particularly relevant to this study as it focuses on examining dialogical ‘struggles’ on Wikipedia over the changing and historically-specific meanings of Down Syndrome, using multimethodological techniques to analyse both records of changes to the Wikipedia page, and to interview moderators and contributors (2010). Our own work draws on Cimini’s approach, asking how different voices represent different ‘idealogues’ and thus how wider social debates can be seen as playing out through the asynchronous and non-linear discussions by diverse networked publics, in Facebook comment sections. In Bakhtin’s terms, it is impossible to separate language out into ideology and stylistic components because discourse is a social phenomenon (Bakhtin 1981, location 3689 of 6377). As such, our meth-
methodological design sought to understand these comments not as text, but as social practice occurring through ‘speech acts’ and social gestures, as well as the circulation of affect – focussing therefore not only on the meanings they convey, but the actions they take.

Methods and data

As of the second quarter of 2018, Facebook had 2.23 billion monthly active users, and was the most popular Online Social Network (OSN) (Wilson, Gosling and Graham 2012; Statista.com). It is rapidly evolving and its use as a research tool requires careful consideration by ethnographers as sites like Facebook have a fluid ‘ecology’ that makes it difficult to identity fieldwork boundaries (Walker 2010). On social media the choice to offer attention to a particular topic or story, depends primarily on its salience in the life worlds of the commentators (Frosh 2018). As such we did not seek to narrow our focus to a particular community, but to instead to a set communication ‘nodes’ around this one news event. To do this we selected the (chronologically) first eight news posts about the Baby Leo case, focusing on the public pages of major New Zealand news outlets running this coverage, and excluding other public Facebook pages (such as parenting pages), or Facebook groups (including those related to Down Syndrome), which were noted to have also shared the stories, but with more limited or targeted audiences. We labelled each of the stories as a ‘data-point’. Each varied in degree of engagement from the public through comments and share, as shown in Table 1.

As medical anthropologists, one of our key interests in this data was in culturally-specific and situated meanings around Down Syndrome, disability, citizenship. Specifically, we were tracking the practices of moral and relational positioning and care, that were both expressive of, and constituted by, these meanings as they emerged around this complex news story. All of the media outlets associated with these eight datapoints were national news outlets although digital technologies are associated almost inextricably with the forces of ‘globalisation’, and just as the story received attention as global news, we also must not assume that the responses to these news stories came only from people living in New Zealand or identifying as New Zealand citizens. This is not necessarily a barrier to an anthropological approach, indeed, ‘anthropologists are in a unique position to study the vernaculars of electronic globalisation’ as media objects and messages move through time and space, articulating identities and lifeworlds (Vokes and Type 2018, 207–215).

Social media makes ‘asynchronous conversation’ possible within and across


Table 1. Datapoints

<table>
<thead>
<tr>
<th>Data point #</th>
<th>Date &amp; Time</th>
<th>Story Headline</th>
<th>News Outlet (via their Facebook page)</th>
<th>Engagement Stats (as of 23rd June 2015 for DP1; 14th October for DP2–8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DP1</td>
<td>Feb 6th 2015</td>
<td>Dad’s mission for baby Leo</td>
<td>Stuff.co.nz</td>
<td>3,106 likes, 156 shares, 196 comments (148 primary, 48 secondary)</td>
</tr>
<tr>
<td>DP2</td>
<td>Feb 7th 2015</td>
<td>Kiwi dad ‘stunned beyond words’ at $450,000 raised to bring down son home</td>
<td>ONE News</td>
<td>5,225 likes, 289 shares, 183 comments (119 primary, 64 secondary)</td>
</tr>
<tr>
<td>DP3</td>
<td>Feb 8th 2015</td>
<td>Armenian mother denies claim she abandoned her down syndrome child</td>
<td>ONE News</td>
<td>262 likes, 22 shares, 139 comments, (83 primary, 56 secondary)</td>
</tr>
<tr>
<td>DP4</td>
<td>Feb 8th 2015</td>
<td>Mother of baby with Down syndrome speaks out</td>
<td>3 News</td>
<td>1,660 likes, 75 shares, 364 comments (221 primary, 143 secondary)</td>
</tr>
<tr>
<td>DP5</td>
<td>Feb 9th 2015</td>
<td>Mum of Down Syndrome baby Leo speaks up</td>
<td>Stuff.co.nz</td>
<td>564 likes, 34 shares, 206 comments (103 primary, 103 secondary)</td>
</tr>
<tr>
<td>DP6</td>
<td>Feb 21st 2015</td>
<td>Baby Leo: The untold story</td>
<td>nzherald.co.nz</td>
<td>454 likes, 55 shares, 382 comments (250 primary, 132 secondary)</td>
</tr>
<tr>
<td>DP7</td>
<td>Mar 1st 2015</td>
<td>Leo’s parents give it a go</td>
<td>Stuff.co.nz</td>
<td>644 likes, 71 shares, 213 comments (145 primary, 67 secondary)</td>
</tr>
<tr>
<td>DP8</td>
<td>Jun 21st 2015</td>
<td>For a few weeks this year...</td>
<td>3 News</td>
<td>466 likes, 17 shares, 87 comments (52 primary, 35 secondary)</td>
</tr>
</tbody>
</table>

networked publics (Recuber 2015, 66). Gillen and Merchant’s (2013, 57) study of Twitter suggest that this offers a ‘partial intersubjectivity’, and Kuo (2018) notes the platforms ‘real-time’ nature was key to its powerful potential as a platform. Of course each social platform has its own norm and expectations of engage-
ment, guided by community behaviour as well as the structural features of the site. Applying the Bakhtinian notion of ‘chronotopes’ (Bakhtin 1982, location 1309 of 6377) provides a somewhat fresh perspective on social media, with room to encompass both aspects. A chronotope is a particular configuration of time and space – as constructed by language (i.e. inherent to a particular narrative or, as other authors have offered, communicatory space). Drawing on this, we argue that platforms such as Facebook have their own separate chronotope ‘time’. This is a chronotope observably related to the news media circuit – as in the way social media activity flurried around ‘breaking news’ stories and then gradually petered out over time – but also distinct from it, in patterned expectations of a timely response unique to the digital. Furthermore, online chronotopes interact with offline chronotopes in unique ways, since people can both step in and out of the online ‘place’ (and time) or as Lee (2016) argues, occupy both at once. The distinct chronotope of Facebook raises practical concerns regarding research methods. The data we dealt with was fluid and shifting. Since we viewed it at some time after the initial story (between 2 days, and 4 months later), there were not a great deal of new comments being added, yet Facebook’s algorithms continually changed how it appeared on our screens each time we logged on, in particular with the order of comments rearranging. Comments could be removed by moderators at any time, usually with no visible trace remaining. Facing this issue, we made the decision to print the material and analyse it from hard copy, so that each researcher could work from the same standardised set of data. This shift of medium undeniably removes it from somewhat of its embedded (online) ethnographic context. In part because of this, we do not consider our study to be a digital ethnography; we were not participants, and at best ‘lurkers’ (Murthy 2008). As such our methodology followed a form of content analysis, and to make this suitable for the ‘dialogical’ analytic framework we employed it was valuable to be able to preserve a sense of the relationship of comments to original story/post, and of the between comments, through these means. Counted in Table 1, ‘primary’ comments we refer to those that commented as a reply to the initial post by the news outlet, while ‘secondary’ we refer to those that commented as a reply to one of the primary comments by another user.

**Analysis**

We analysed the eight original news stories, as well as responses to them on Facebook (comprising all primary and secondary comments). This included analysis of 1770 comments in total, across the eight datapoints. The full dataset was initially coded by the first author, before a closer analysis of DP1 and DP2 was undertaken by the first and second author.
Figure 1. Example of the original post and first section of comments for DP1, as it appeared on screen (and on our print-outs, for coding and analysis). Note that in this version, primary comments are shown, while secondary comments appear as ‘replies’; these were opened out for inclusion in the analysis during coding.
Figure 2. Example of the original post and first section of comments for DP6, as it appeared on screen (and on our print-outs, for coding and analysis).
Our dialogical approach to this analysis required a re-thinking of a standard thematic coding approach. This modified analysis involved first undertaking a standard thematic analysis (drawing on awareness of existing media tropes in New Zealand, from previous work [Wardell et al. 2014]), and then completing a second round of analysis which coded for the dialogical qualities of the comments. Initial coding was conducted independently between the researchers, before emerging codes were discussed. Codes were compared back together once again, and through an iterative process the list of key themes was honed. The emerging thematic codes are shown in Table 2.

<table>
<thead>
<tr>
<th>Disability Cultural Frames</th>
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<tr>
<td>Visualness /Visability</td>
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<tr>
<td>Innocence /Perfection</td>
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<tr>
<td>Prenatal Screening</td>
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<tr>
<td>Representational Politics (including language)</td>
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<tr>
<th>Care</th>
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<tbody>
<tr>
<td>Financial cost</td>
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<tr>
<td>Gendered care</td>
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<tr>
<td>Choice</td>
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<tr>
<td>Quality of Life</td>
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<tr>
<th>Citizenship/Belonging</th>
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<tr>
<td>Moral evaluations</td>
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<td>Compassion</td>
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<tr>
<td>Judgement</td>
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<tr>
<td>Perspective/Relativism</td>
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<td>Public/private</td>
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In order to highlight the dialogical features of the text/s, we paid particular attention to the relationship between comments, including the ‘pockets’ of secondary comments, around particularly controversial primary comments. Each time we asked, what it was about this statement that elicited attention and response, and what the nature of the exchange that occurred: Antagonistic? Adversarial? Jovial? Coalescing? (Cimini 2010, Jemielniak 2014). We coded each section for tone and style of interaction, with the emerging codes and sub-codes as shown in Table 3.

We did not wish to keep these two sets of codes separate, but to bring a sense of the dialogical to the thematic coding also, so the next step was to make one final round of coding which sought to understand how particular thematic
meanings were articulated in and through particular dialogical topes – for example, the expression of citizenship and belonging via addressivity, or moral judgement via abuse, as we discuss in the next section. Situated in real social worlds, and referencing wider political, moral, and social debates, we use these to examine the struggles of meaning over gendered dimensions of care and responsibility, cultural relativism in relation to the meaning of disability, and citizenship and belonging amidst both nationalistic and cosmopolitan values. Most of our quoted examples are drawn from Datapoints 1 and 2, but the broader sense of our argument draws from all eight news stories and the 1770 comments that accompanied them. Although there is a reasonable expectation for those posting on these public Facebook pages that their comments will be public also, in removing them from their original social context we have chosen to represent all comments here anonymously, barring one significant example made by a public figure. We have made no alterations to the original text, except to correct spelling – not as a rule, but in the few cases where it threatened comprehension.

FINDINGS AND DISCUSSION

‘Welcome home Leo’: addressivity and words of authority

In his discussion of speech genres, Bakhtin argues that “addressivity, the quality of turning to someone, is a constitutive feature of the utterance; without it the utterance does not and cannot exist” (Bakhtin 1986, 99, cited in Gillen and Merchant 2013, 14). The particular forms of this addressivity, and the addressees

<table>
<thead>
<tr>
<th>Agreement</th>
<th>Disagreement</th>
<th>Persuasion</th>
<th>Correction</th>
<th>Questions</th>
<th>Abuse</th>
<th>Laughter/parody</th>
<th>Addressivity</th>
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<td>• Declaring Blessing</td>
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<td>• Collective Language Use</td>
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</tbody>
</table>
involved, can prove a definitive feature of different speech genres, he goes on to argue. In the vernacular genre of online comments, we must therefore ask to whom the various posters are ‘turning’ as they speak out their opinions and interpretations about the news story. Who are the addressees? One obvious answer is that they are speaking to each other. There is, at least in appearance, a back-and-forth, quasi-linear progression in the way they appear on the screen. Many comments are posted as ‘replies’ to earlier comments – creating ‘pockets’ of conversation – and some posts respond to other individual posters by name. However many comments address people who are not present as part of the Facebook conversation – *i.e.* strangers and imagined others. For example, there was a flurry of corrective comments addressed to the news outlet and/or journalist responsible for the One News (DP2) story, which formed part of a rapid and vigorous debate on the (lack of) people-first language in news media reporting, including in the some of the original headlines around this story. A comment on DP1 (shown in Figure 1) indicates the commenter is responding to a revision to the headline on this article to, *or* comparing it with the other problematic language on DP2. Our interest, however, is primarily in the overwhelming number of comments that addressed not the journalists or host site, but the individuals featured in the story.

Frequently we observed comments which addressed Samuel Forrest, Ruzan Forrest, or quite often, baby Leo himself, for example, ‘Welcome little man – Dad = you rock dude’, ‘Bring this baby home bro!’ Comments such as these used a variety of different speech acts to command, commend, and to declare blessings. Well-wishes spoken to the father and son in these comments range from standard secular (‘Good luck to you and your son’, ‘best wishes for the future’); religious (‘God bless’); and colloquial (‘Oh Bless’) to culturally specific aphorisms (‘hope he grows up to be an All Black’, ‘Kia Kaha’). The trope of ‘declaring blessings’, was closely related to ‘declaring welcome’: those comments that offer positive messages of invitation, acceptance, affirmation and belonging. ‘Welcome home Leo’ many people simply state. ‘Welcome home Leo… good on you Dad’; ‘We will love you in New Zealand’. It is when we consider addressivity – to whom the comments claim to speak to – in conjunction with ‘voice’ – whom the comments claim to speak *as* or *for* – that we can begin to elucidate the significance of such comments as part of the polyphonic expression and negotiation of key ideologies around citizenship, belonging, and collective care responsibilities.

One reason these seemingly simple statements of welcome relate so significantly to those broader meanings is the authority lent to them by a collective voice adopted. Although comments are made only by individuals (not Facebook
groups or pages), a strong number of comments adopt a collective voice – often speaking as if on behalf of the imagined community of the nation, through the common use of plural pronouns such as ‘we’, and ‘our’. These were linked to statements of (collective) ‘welcome’ in which many voices/ideologies appear to coalesce, cohere, and at other times conflict. Indeed the idea of ‘welcome’ is a significant one in the New Zealand psyche at this moment in time; both in relation to the ideological project of national identity building, and in relation to a number of salient yet controversial events that represent significant parts of the contextual landscape of the language we analyse in these Facebook comments, and which we unpack later. A Bakhtinian approach impels us to attend closely to both.

As a speech act, an utterance of ‘welcome’ is something we encounter ‘with its authority already fused to it’ as Bakhtin would describe – giving it a performative and binding quality. Bakhtin (1981, location 4772 of 6377) calls this kind of authoritative word a ‘word of the fathers’ – a prior discourse with a special power that he says is exemplified in religious dogma and scientific ‘truth’ alike. Notably we also observed the use of the Te Reo Māori term, ‘Haere Mai’, which is most commonly translated to ‘welcome’ in English. This phrase is utilised as a powerful ceremonial speech act in a wide variety of formal contexts in New Zealand, including in political and diplomatic situations as well as being sung/cried as part of the karanga (welcoming call) at the start of a pōwhiri – a Māori ceremony to bring visitors onto a marae (communal Māori space) – forming a powerful utterance that functions to establish a relationship between manuhiri (visitors/guests) and the tangata whenua (people of the land) who are hosting them. In this context we suggest (as Pākehā researchers) it represents protection, responsibility, and relationship; and also the authority of the speaker/caller to offer these. Understanding the context for the use of the term ‘haere mai’ alongside the English language term ‘welcome’ in these comments, reflects Becker’s (1992) notion of ‘prior text’ which addresses the significance of memory for communicative practice – positing that speech acts always echo an invisible prior text, recalling collective past experience (cited in Williamson 2016, 75). Along with formal traditions, wider pop cultural references can also form part of this prior text; such as the 2005 song by Kiwi icon Sir Dave Dobbyn, entitled Welcome Home, which quickly become a recognisable modern classic in New Zealand, and was later (in 2017) also translated into and sung in Māori.

Bakhtin (1981, location 4793 of 6377) argues that it is difficult to incorporate semantic changes into authoritative utterances, as the idea must be accepted as a whole rather than divided. However Bakhtin was interested not only in authority, but also in persuasiveness, writing that these were rarely seen in
unity. He claims that publications, institutions, and individuals are all capable of ‘exploit[ing] the intentional possibilities of language through the medium of their specific concrete instancing’ in order to express their world view (Bakhtin 1981, location 4083 of 6377). Thus alongside ‘welcome’, we now explore the word ‘home’. The two words were inextricable from one another in the context of these comments, and yet while ‘welcome’ functions with fixed and prior authority, the word ‘home’ has much more room for semantic contestation.

‘Safe flight to our motherland’ – Citizenship and home as a ‘word with a loophole’

The title of the Go Fund Me campaign around which the story which initially focussed, was ‘Bring Leo Home’, so it is perhaps unsurprising that this term, and concept, echoed frequently through the comments too. ‘You and your son Leo can come back home to NZ now’ one commentor said while another opined ‘He’s a kiwi, bring him home’. Yet the meaning of the word ‘home’ is fragile, contested, and contextually dependent (George and Fitzgerald 2012) – closely fitting Bakhtin’s definition of a word-with-a-loophole (Gillen and Merchant 2013). A word-with-loophole is a word within which a dialogue can be understood to take place even within that single word (Pechey 2006). In the Facebook comments on the Baby Leo story, we show the multivocality of the word ‘home’ in its use as part of a dialogue around citizenship, belonging, care and collective responsibility.

Home is a heavily affective term. Indeed, with the visual languages of Facebook comments taken into account, abundant smiley face and heart emojis on these posts (see Figure 1) are no less significant than the words they accompany. In New Zealand, Samuel and Leo are assured ‘Bring baby home where he belongs and will be loved by all’; ‘Bring him home babes bring him home he’ll get all the love he needs right here in nz!’; ‘Welcome sweet home! Your country will be safe and support you and his father’; and ‘man, bless you both, a great future will await you both when you get home, where the community will embrace you both xx’. The idea of home is linked to a utopian vision of New Zealand that is part of the nation-building identity project the country is engaged in – drawing on a long-standing and powerful “humanitarian myth” about the New Zealand welfare state, which typically obscures any limitations or barriers, and the unmet needs of some within it (McClure 1998, p258). Indeed many of these comments uncritically depict a state of absolute love, care, and support existing in this imagined realm of New Zealand ‘home’.

Some of the speech acts laid out above not only convey this belief, but again use a collective voice, to assert, declare, and promise it. Yet collective ‘voice’ is
in fact ‘voices’ – some of whom frame home differently. We observed a number of commentors bring up concerns about the financial cost of baby Leo’s care to the nation, echoing longstanding political and social discourses of disability as a social drain (Collins 2016). Others responded to these comments to disagree, admonish, or persuade. For example, after one primary comment about costs to the ‘tax-payer’, a flurry of secondary comments flowed in below, discussing government spending, tax cuts, and with one responder arguing:

the dads [sic] from nz so they both deserve whatever financial assistance we have here everyone else gets it!! So this we biu [sic] deserves it to [sic]. Bring the wee man home! He deserves to be in an understanding country

Key here, alongside the word home, is the word ‘deserve’. ‘Deserve’ was a word that emerged excessively throughout the Facebook comments we analysed, so much so that it formed an initial code, which was later modified for inclusion under other codes to instead capture the nuance of the criteria of deservingness (of assistance and care) that was being debated. We found that deservingness in this case was clearly closely related to belonging, which can in turn be constructed in several ways; through identity, affect, virtue, need, and legal citizenship.

Berliner and Kenworthy (2017) discuss how the crafting of ‘deservingness’ is often key for those engaging in crowdfunding campaigns, and indeed it is a persistent theme in much contemporary crowdfunding research. More widely, Jensen and Petersen (2017) discuss what they call a deservingness ‘heuristic’ and argue that it is an overriding factor in public opinion around the recipients of social benefit. McClure (1998) traces a long history of reckoning with ‘deservingness’ in New Zealand, in relation to both charitable organisations and state welfare policy. Willen (2012, 807) calls upon contemporary social scientists to continue to ‘investigate how health-related deservingness is reckoned’, acknowledging this as an issue significant to healthcare delivery more broadly with an emerging dichotomy of health care as ‘the domain of social justice’ versus ‘a component of market economy’ (Sargent 2012, 55). Drawing on her own research, Willen (2012) discusses the way migration and il/legal-ity highlights the need to differentiate ‘deservingness’ as part of situationally specific, vernacular moral arguments from ‘entitlement’ as formal legal rights based on universalising juridical arguments. Our analysis shows that both of these appear and interrelate in the space of Facebook news media pages.

Citizenship is ‘a crucial dimension of social, political and moral subjectivity’ (Muehlebach 2012, 18) and as Rahm (2019, 61) writes, it is not a neutral con-
cept but rather as Trnka, Dureau and Park (2013, 2) have noted ‘the making of citizens, citizenry and citizenship is an inherently political and constant process masquerading as inevitable, stable, natural entities consisting of the right persons in the right spaces’. In these Facebook conversations we see ideas of citizenship being similarly challenged. At times belonging seemed to be established on the grounds of a self – or peer-established identification or recognition – ‘Kiwi through and through !!!’ commentors declare of the father for example. This was often justified through emphasis on Samuel’s embodiment of cherished qualities of fairness, commitment, altruism, that are socially constructed as inherently ‘kiwi’ – the behavioural markers of New Zealand identity/belonging. As Samuel’s virtues had been heralded internationally through the viral attention to his campaign, emphasis on his ‘kiwiness’ was a way of associating his positive attributes with a collective national identity, again aiding the nation-building project.

Citizenship is also about both rights and responsibilities. There is a dynamic relationship between the perceived vulnerability of baby Leo, and the invocation of these identity-constitutive values among the collective ‘we’ of commentors. In other words, at times it appeared that his deservingness was being established primarily based on his need, as a factor that established an affective form of citizenship. This approach called to the believed-in altruism and fairness of the collectivity that responded, to generate a sense of responsibility and care that was then enacted in words of welcome. At other times the extension of ‘welcome’ and care was embedded in forms of belonging tied to legally-based discourses of citizenship. ‘I am so glad that his father is a kiwi so that the little one can have the life he deserves in New Zealand’ one person stated. This reflects legal citizenship as a bureaucratic relationship with the state, that is itself a form of symbolic capital – formalising belonging to place and space (Blanch 2020, 166). Another invoked the idea of this legal-bureaucratic framework as the basis for relations of care, more ambiguously: ‘Just need to bring bubs home and good old nz tax payer welfare will kick in just make sure get nz passport for bubs so costly be an getting citizenship for bubs’. Clearly the contestation of belonging in relation to responsibility often relates to questions of financial support. For example, when one commentor asserts Leo’s (lack of) entitlement to care in NZ, saying ‘baby isn’t kiwi as not born here to not eligible to come’, others are quick to refute this on the basis of his father’s citizenship both in cultural terms (as a ‘kiwi dad’) and economic terms (as a ‘nz tax paying dad’). Baby Leo himself is also frequently addressed as a kiwi by right of his father’s nationality or, put differently, as a prospective citizen: ‘remember, he will be a new zealander’ as one person wrote [emphasis ours]. This may reflect a ‘pending’ formalisation of the baby’s citizenship, or a history of young people being seen as not-yet-citizens,
or citizens in becoming (Blanch 2020). More broadly it reflects a persistent ambiguity around citizenship.

The conditions on ‘welcome’

Ways of constituting inclusion and exclusion can be local and dynamic – depending on various geopolitical and ideological factors (Willen 2012). The welcome extended in these comments to Baby Leo and his father represents an authoritative mobilisation of somewhat utopian discourses of New Zealand as a nation of progressive acceptance and care, which is constructed in part via a contrast with life ‘over there’ in Armenia, described as a ‘backwards’ and intolerant culture, working in opposition to good, right, and natural practices of care. As one person wrote:

How oppressive is the culture that the mother could not allow herself the natural responses to hold her newborn and feel the love that normally exists.

Many comments emphasise the extremity of difference (‘we could never imagine’) and the powerful effects of cultural forces, referring to ‘the system’ and ‘conditioning’ that is ‘deeply engrained’. At face value this lines up with Seu’s study of the responses of ordinary citizens to human rights violations, which describes the ‘symbolic function of drawing moral boundaries for the purpose of moral exclusion’ (2012, 1172). Seu specifically identifies a discursive trope she labels ‘in countries like that’ – which bears a striking resonance with many comments we observed on the Baby Leo story. Seu (2012) emphasises that these symbolic boundaries position then resist or ‘block’ empathy towards ‘them’. Yet there was more complexity in the responses we analysed, where the otherness of ‘them’ actually elicited rather than blocked compassion (albeit retaining a sense of superiority, and thus functioning more as sympathy than empathy).

In many comments Leo’s mother Ruzan was often framed as a unnatural, unfeeling monster (a significantly gendered critique), and became the subject of much abuse. This shows how the mobilisation of collective sympathy is contingent, with responsibility being abrogated if the victim themselves is ‘other’. Yet it was notable that those voicing most compassion towards Ruzan often utilised references to her cultural socialization and setting to de-emphasise the element of choice for her actions and there were a range of comments that emphasised the presumed cultural or structural intolerance towards disabled people in Armenia, while extending compassion to Leo (and sometimes Ruzan) as victims of this culture. Positioning baby Baby Leo in particular as a ‘deserving
victim’ of the un-caringness of ‘those countries’ is an act of positioning only possible when the moral boundaries between us and them are clearly denoted (Seu 2012, 1176). In choosing to frame the crowdfunding campaign around bringing baby Leo from ‘over there’ to ‘back here’, the negativity and vitriol did not then function in opposition to the warm discourses of welcome, but was mutually constitutive – of affects of care towards baby Leo, and of a utopian humanitarian vision of New Zealand.

The convenient contrast between the Armenian mother who rejected her baby, and the Kiwi father who accepted him, assisted in affirming the utopian vision of New Zealand as an accepting and welcoming society ‘to all’, but also took on cosmopolitan aspects at times.

May the community in Auckland where they settle welcome them with open arms… after all, it really does take a village to raise a child. The world wide one is already helping to do that – kia kaha xx

Here the idea of welcome (embodied in ‘open arms’) is linked to the reference to a proverb stating ‘it takes a village to raise a child’, as prior text – emphasising the collective responsibility of ‘the community’ or ‘village’ to children. ‘Bring your baby back into the arms of Aotearoa to be nurtured and raised by this global village’ another commentor impels. Here Aotearoa New Zealand is both part of and in itself is the global village; a moment of identity-building, imbued with cosmopolitan values and language. It is not only the scale of the language, but as Ahmed (2004, 6) notes, it is the very intensity of the commenters’ attachments – expressed in warmth, compassion, welcome, and care for Baby Leo – that can be seen ‘aligning individuals with collectives’ and ‘imagined subjects with rights’. In this way moral affects such as compassion and care, were mobilised most effectively a powerfully performative utterance of (collective) welcome which acted not only upon the intended addressee, but upon the speakers, and other readers/listeners. Specifically, it aligned the commentors themselves with Aotearoa as a cosmopolitan collective, and Samuel and Leo as subjects ‘imagined’ by these commenters, with rights to care and welcome via these affective attachments.

One comment stood out as singularly significant in relation to the wider national discourses of rights discourses, and ‘welcome’, from that moment in time:

This is so wonderful to see from Kiwis and the rest of the world as we build a culture of inclusion. Unfortunately the majority of kiwi babies with Down syndrome are still abandoned before birth because of the
bias of prejudice, but as we see here, all life has value and should be welcomed and celebrated. – Mike Sullivan (DP1)

The warm, positive language of his comment *i.e.* ‘wonderful’, ‘welcomed and celebrated’ skilfully echoes existing comments in their expression of acceptance and care. However he does so in a way that subtly subverts or challenges the utopian vision of New Zealand that earlier voices have presented, through a sideways reference (‘abandoned before birth’) to New Zealand’s then relatively new prenatal screening programme, and its association with pregnancy termination. Many of those reading the comments would not know, as the researchers did, that Mike Sullivan is the founder of and spokesperson for the ‘Saving Downs’ advocacy group. This group, of whom we have interviewed several members in prior research (Fitzgerald, Wardell and Legge 2017), have been closely concerned with protesting the screening programme, even launching a case to the International Criminal Court in 2012 to claim it constituted a eugenic programme targeting people with Down Syndrome. Sullivan’s comment here highlights the fact that the ‘welcome and acceptance’ of baby Leo is far from unconditional, even in New Zealand. He uses the powerful idea of ‘welcome’ that echoes throughout the conversation to voice an ideology which our previous work has identified as central to the ethical orientations of this group: that of the ‘unconditional welcome of newborns’ (Fitzgerald, Wardell and Legge 2017). Sullivan’s appeal is for recognition of an in-utero biological citizenship based on a shared genetic marker for citizens with Down Syndrome. What is also striking about Mike’s comment is that the language his comment skilfully employs makes it ‘free-standing’ – knowledge of Sullivan’s own political activism is not required to make the note intelligible amidst the broader negotiation and contestation of the ideas in the thread and it successfully complicates the adjacent areas of debate around disability and citizenship in New Zealand.

There are resonances here with ethical debates about belonging, citizenship and care, disability and responsibility, which relate not only to debates and public media coverage about prenatal screening programmes (particularly prominent in the five years prior to the baby Leo story), but also debates arising from changes to state healthcare and education services, including via the neoliberal restructuring (often adjacent to mainstreaming policies), which has the withdrawal or relocation of support for people with disabilities. In addition, the media has specifically reported on the refusal of visas to the families of those with Down Syndrome and other disabilities, from New Zealand and Australia in recent times (Collins 2016, Truu 2019). Indeed one newspaper headline about a family who were all given visas, with the exception of their daughter who has Down Syndrome, read: ‘Welcome to NZ, but not your daughter with
Down Syndrome’ (ODT 2018), subverting the same powerful language of welcome observed in our case study, to make a critical point. Considering this wider context in which the threads emerge, we assert that as both a classificatory mode and as an identity marker, citizenship remains conceptually elusive (Trnka, Dureau and Park 2013, p. 6). Amidst a global refugee crisis, debates about moral responsibility in relation to refugees in New Zealand (McCarthy 2020) and around the world, highlight the relationships between the politics of difference, citizenship, and belonging, and what emerges as in fact being very conditional forms of care and ‘welcome’.

**Negotiating the ethics of neoliberalism through crowdfunding**

Debates around who has the right to receive care, and who has the responsibility to give care, were heavily embedded in neoliberal moral regimes and as such relied heavily on distinctions between what is ‘public’ and what is ‘private’. This is complicated by the locus of the debate on a public page, responding to a public news story, spurred by a publicly visible financial campaign by and for private individuals. It ties into some of the moral logic of crowdfunding, in promoting marketized (and hyper-individualized) care structures. By bringing this ‘private’ family situation to the attention of various networked publics through a Go Fund Me page, Samuel Forest is inviting the public to not only feel care but to take on the responsibility for enacting care – through individually choosing to make a financial donation, within their capacity as private citizens. Thus it is a specific version of neoliberal citizenship that is being debated here, which also makes the care recipients accountable to other citizens, through networked responsibility. It is as part of this process that care recipients are presented for public evaluation and scrutiny, as we saw occurring in the comments we analysed.

The positive moral qualities of Samuel’s actions were constructed by a large number of voices in the comments. Their emphasis on qualities of resilience, and responsibility, are reflective of a the widely discussed neoliberal responsibilization (Trnka and Trundle 2014), even while they undoubtedly draw on other pre-existing and locally-specific moral systems (and other competing forms of responsibility) including, gendered ideas of care, and the ‘good kiwi’ father. The aspects that are specific to a neoliberalised moral economy, are the provision of/for the enactment of kin-based care through private financial mechanisms, with some commentors seeming to read Samuel as enacting good neoliberal citizenship, by pro-actively seeking of innovative solutions for the support and care of his child. The matter remains private (in the sense of care costs being negotiated between private citizens) even while public in the
sense of being brought to a collective who frequently speak with a collective voice – on behalf of ‘New Zealand’. The many media articles, and processes of public engagement with them, can be argued to be a part of the practices of audit and accountability that accompany neoliberal notions of the responsible individual (Trnka and Trundle 2014). Indeed in the following month, in stories both within and outside of this dataset, funders, media, and the general public questioned how the Forrests’ funds were managed and spent: and specifically, if they were being used ‘irresponsibly’ (Taylor 2015).

The rights and responsibilities associated with receiving public care, and offering it, are also debated in some pockets of Facebook conversation: ‘So what if he has to ask the public for help’ someone asks. Taking a persuasive tone, another impels others to ‘put your thoughts where your wallets are and shell out some mullah’. It is worth considering then the context in which crowdfunding campaigns to cover medical and other care expenses, are becoming increasingly common in Canada, the USA and UK (Berliner and Kenworthy 2017, Lukk, Schneiderhan and Soares 2018). The shift from ‘cradle to grave’ welfare policies in New Zealand in the 50s and 60s to a neoliberal political economic in the late 80s has encompassed a moral shift, not just an economic one – emphasising meritocratic principles and ‘individual responsibility for one’s own welfare and that of one’s relatives’ (Jaye, Fitzgerald and George 2018, 72). ‘Dependence’ has become a dirty word in the neoliberal moral economy (Bauman 2005, in Muehlebach 2012, 49), and this is another discursive risk for Samuel and Leo’s complex performances of virtue and vulnerability, in relation to the specific heightened needs associated with Leo’s disability. It is unsurprising that some commentators are critical of Samuel’s public request for money, as well as Leo’s assumed reliance on public health care once he was brought to New Zealand (where he had not even been before, despite rhetoric framing his proposed travel to New Zealand as a ‘return’ or homecoming). Berliner and Kenworthy (2017) argue that crowdfunding erodes claims for social protection, and yet there is always room for multiple and intersecting forms of responsibility, as Trundle and Trnka argue (2014). In this case, fraught discussions of kinship and carer responsibility sit alongside those about citizenship, state funding and support, and also a wider public responsibility to ‘pull out your wallets’. Part of the moral restructuring of a neoliberal system is that new collectivities can emerge, along with new spaces for collective action (Trundle and Trnka 2014) and crowdfunding can be part of this (Gomez-Diago 2016). The public has their own opportunity to enact good moral citizenship by donating to Baby Leo’s campaign. Their moral positioning in this case is distinctly neoliberal; they are free, individual, private citizens who choose to give. This resonates with Muehlebach’s (2012, 7) discussion of the qualities of the ‘moral neoliberal’,
which highlights both individual responsibility and a ‘fantasy of gifting’ that at the same time reveals crowdfunding as emblematic of the ‘faith in markets to govern social life’ (Trnka and Trundle 2014, 137).

Crowdfunding often relies on the construction of a ‘worthy’ illness, as well as a deserving recipient (Berliner and Kenworthy 2017, Lukk, Schneiderhan and Soares 2018). Can we then understand the largely warm, positive reception of both the crowdfunding campaign, and the media stories about it, as representing a designation of Down Syndrome as worthy? The stereotypical (and contestable [see Fidler 2006]) association of people with Down Syndrome with innocence, happiness, and goodness may contribute to this, and indeed references to the perfection, innocence, and sweetness of baby Leo, are heavily present all throughout the comments. This allows the audience to align themselves with politically specific moral virtues (of altruism, care, and free gifting of money), authorised by Leo’s need, blamelessness, and vulnerability. Trundle, Gibson and Bell’s (2016) article insists that medical anthropologists, among others, have often over-simplified the concept of vulnerability as negative, and related to powerlessness. Drawing on Gibson’s (2011) work, they advocate for a broadened conception of vulnerability which acknowledges fundamental human relations of interdependence, and the way that vulnerability can invoke care and solidarity within networks. As such it can be both useful and powerful; and in this case, strategically marketable, with the news stories associated with the crowdfunding campaign functioning as a sort of extended PR for the campaign page, and the comments section not only a way to measure ‘buy in’ of the market audience, but also to view their active co-construction of meanings about people with Down Syndrome (and their families), and their own positioning in relation to these.

CONCLUSION

Discourse is defined by movement, and closely entangled with affect, which Ahmed (2004) notes can both circulate and attach to particular bodies that become ‘sticky’ with meaning. We contend that people with Down Syndrome can be considered one such category of person, around whom not only meaning but affect circulates in digital public spheres. Cimini’s (2010) work about the changing and contested meaning of Down Syndrome on Wikipedia can be read as evidence of this ‘stickiness’ as well and shows how negative (mocking, vitriolic, and hateful) sentiment recurs through written and visual edits to the page and must be managed. However in our study of Facebook, despite pockets of abuse (and some comments likely removed by moderators) we see predominantly, and no less significantly, a circulation of positive (warm, caring,
compassionate) albeit somewhat naïve or utopian sentiment towards baby Leo Forrest. Those commenting on the baby Leo story on Facebook engage in what Berlant describes as a mode of ambient citizenship – ‘a mode of belonging, … that circulates through and around the political in formal and informal ways with an affective, emotional, economic, and juridical force [both] clarifying and diffuse’ (Berlant 2014, 230). In attracting thousands of Facebook comments from strangers, the persons of Baby Leo, Samuel, and Ruzan at the centre of this story demonstrate the movement and circulation of affect between people, via digital spaces and practices, relation to particular socially-positioned bodies, and in turn reveal the way this process works to produce or reproducing certain sets of social relations – of care or belonging.

While subsequent stories of the family’s situation have continued to appear (3 News 2016, Hobbs 2016, Taylor 2016), from a Bakhtinian dialogical perspective (and an anthropological one) we know there is no such thing as an ‘ending’. Instead, the story was, and is, being told, retold, and struggled over in a very public terrain, by and through diverse networked publics. The multiple voices in this digital public sphere represent ideas about the rights and responsibilities of care for those with disabilities, the criteria for citizenship, social attitudes towards people with disabilities, the qualities of contemporary New Zealand as a nation, and the moral ‘right’ in charity or welfare. Rather than individual authoritative statements, it is the spaces and struggle between various typically informal or low-keyed comments – along with their techniques of voice and addressivity – which are revealed as locating the issues circulating around this one story of this one family within wider socio-political conversations about who will be welcomed, who will be cared for, and who gets to decide.

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NOTES

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3 One of the main platforms of crowdfunding at the time of writing.

REFERENCES


