

<b>Institution:</b> Newcastle University		
<b>Unit of Assessment:</b> 21 Sociology		
<b>Title of case study:</b> Nowhere To Go: Collaborating with Families and Disabled People, User Organisations and Local Government in the North East to Implement Policies to Improve Provision of Accessible Toilets		
<b>Period when the underpinning research was undertaken:</b> 2003-2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b> Janice McLaughlin	<b>Role(s) (e.g. job title):</b> Professor of Sociology	<b>Period(s) employed by submitting HEI:</b> September 2001-ongoing
<b>Period when the claimed impact occurred:</b> 2017-2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<p><b>1. Summary of the impact</b>          In the North East of England the severity of welfare austerity has led to significant cuts to local authority budgets. This has been particularly difficult for families with disabled members who have found their opportunities for social inclusion in society reduced. It has also increased the pressures on families to both manage the loss of support and to advocate for their needs and rights. McLaughlin's research with families and disabled people, particularly children, and third sector organisations that advocate for them, captures both their experiences of austerity and of campaigning. Drawing from that research and working with families and organisations, her work has produced change in regional public policy. One area where the research approach is leading to direct change in local government policy is the Nowhere To Go collaboration with disability and carer groups and North East local authorities to improve the provision and accessibility of public toilets. These policy changes have had a proven positive impact on the approach to and implementation of specific public services, which will, post Covid-19 (see Covid-19 impact statement), reduce the social exclusion of disabled people and their families.</p>		
<p><b>2. Underpinning research</b>          Since coming to Newcastle University in 2001, the lives of families with disabled children in the North East have been at the heart of McLaughlin's research [PUB 1 and PUB 2]. Three ESRC funded projects have produced new insights that have contributed to medical sociology and to critical disability studies, as well as areas examining embodiment, family and kinship studies and youth transitions. The approaches taken in this portfolio of research are grounded in a core commitment to being <b>inclusive in design</b> and <b>impactful in outcomes</b>.</p> <p>Key insights from the research include:</p> <ol style="list-style-type: none"> <li><b>1. The paucity of support provided by local and national state agencies and how this heightens the isolation and marginalisation of families.</b> McLaughlin has shown how crucial limitations in disability support and public services produce social exclusion for families with disabled children and inhibit their participation as equal citizens in society [PUB 1]. She has documented the ways in which families are required to fill the gaps in social care provision, something that has been exacerbated by welfare austerity. She has also captured the multiple roles carers must adopt, including that of being administrators and advocates for their children, as they navigate the complexities of welfare benefits and areas such as educational support [PUB 3].</li> <li><b>2. The damage stigma has on the lives of disabled young people and their families.</b> While stigma is a well-established concept across medical sociology and disability studies, McLaughlin's research brings to the fore its embodied dynamics and locates its significance in broader socio-economic contexts of welfare austerity and neo-liberalism. Her work highlights the 'embodied conditionality' within state and social recognition of disabled people as citizens. This lack of recognition stems from the ways</li> </ol>		

in which their embodiment does not match the norm of the independent, self-sufficient individual agent celebrated by the neo-liberal state [PUB 4 and PUB 5].

**3. The value of using varied and collaborative approaches to research design when working with families and disabled children and young people in research.**

McLaughlin's research deploys methodological approaches that are participant-led and varied, including longitudinal narrative interviews, participant and non-participant observation, journal writing and creative visual methods. For example, she has used drawing, photography work and craft making with disabled young people to go beyond the written word, creating a space for participants to represent the values they embody within their identity – values that provide a counter to the stigma they experience [PUB 6].

**4. The necessity of building long term partnerships with organisations that are run by or work with disabled children and their families to ensure findings influence policy and practice.** Her research is informed by long term partnerships with: (a) organisations that support families and disabled children and young people, including Contact a Family North East (unfortunately now closed), Disability North, and Investing in Children; (b) healthcare providers including Northern Genetics Service and the Newcastle Hospitals NHS Foundation Trust; and (c) local authorities including Newcastle City Council and Northumberland County Council.

**5. Challenging the conditional citizenship of disabled people and their families by advocating for better conceptual frameworks to recognise their capacities to be citizens with the right to participate in both society and policies and practices that are supposed to benefit them.** McLaughlin makes a compelling case for moving away from basing capacity and rights justifications on liberal individualistic grounds. Instead, she draws from and contributes to feminist arguments about the **relationality of citizenship** by proposing that within egalitarian conditions, the relationships that disabled people exist within, including their families, can enable them to exercise rights and be fully recognised as citizens [PUB 1].

### 3. References to the research

Publications listed below collectively represent research of at least 2\* quality based on REF criterion of significance, rigour and originality, with all of them coming out of ESRC funded research projects and rigorously reviewed in high quality journals/academic publishers. All have been through external and internal review processes that identified them as submittable to REF2014 or REF2021.

[PUB 1] McLaughlin, J., Coleman-Fountain, E. and Clavering, E.K. (2016) *Disabled Childhoods: Monitoring Difference and Emerging Identities*. London: Routledge. ISBN-9781138494503.

Available on request

[PUB 2] McLaughlin, J., Goodley, D., Clavering, E.K. and Fisher, P. (2008) *Families Raising Disabled Children: Values of Enabling Care and Social Justice*. Basingstoke: Palgrave. ISBN-10 0230551459. Available on request

[PUB 3] McLaughlin, J. (2006) 'Conceptualising intensive caring activities: The changing lives of families with young disabled children'. *Sociological Research Online*. 11 (1).

<https://journals.sagepub.com/doi/abs/10.5153/sro.1219>

[PUB 4] McLaughlin, J. and Coleman-Fountain, E. (2014) 'The unfinished body: The medical and social reshaping of disabled young bodies'. *Social Science and Medicine*. 120 (November) 76–84. <http://dx.doi.org/10.1016/j.socscimed.2014.09.012>

[PUB 5] McLaughlin, J. (2017) 'The medical reshaping of disabled bodies as a response to stigma and a route to normality'. *Medical Humanities*. 43: 244-250.

<http://dx.doi.org/10.1136/medhum-2016-011065>

[PUB 6] McLaughlin, J. and Coleman-Fountain, E. (2018) 'Visual methods and voice in disabled childhoods research: troubling narrative authenticity'. *Qualitative Research*. 19(4) 363-3821.

<https://doi.org/10.1177/0038038519868630>

**GRANTS:**

1. Janice McLaughlin (PI), Allan Colver (Co-I) and Patrick Olivier (Co-I) 'Embodied Selves in Transition: Disabled Young Bodies', funded by the Economic and Social Research Council, May 2011-October 2013 (GBP229,000)
2. Janice McLaughlin (PI), Erica Haimes (Co-I) and Michael Wright (Co-I) 'Kinship and Genetic Journeys: A Study of the Experiences of Families who are Referred to Paediatric Genetics', funded by the Economic and Social Research Council, October 2008-September 2011 (GBP395,000)
3. Dan Goodley (PI) and Janice McLaughlin (Co-I) 'Professionals and Disabled Babies: Identifying Enabling Care', funded by the Economic and Social Research Council, June 2003-May 2006 (GBP309,000)

**4. Details of the impact**

McLaughlin's research and its associated impact began and has remained centred in the North East. The North East is a region where the impacts of welfare austerity over the last decade have been particularly severe for families with disabled members. 25% of people in the North East are disabled, the highest percentage in England, while a [79% cut in central government funding](#) to North East local authorities since 2010 have left them severely limited in their capacity to provide the public services disabled people and their families need. This is where McLaughlin's work has been able to have significant impact by capturing the costs of austerity on families in multiple areas, including impacts of the loss of public services on greater social exclusion. By facilitating collaboration between local government and families, she ensures a level of knowledge exchange that enables concrete change in policy and the provision of services. The case study highlights one area of important policy impact, which uses her research approach and knowledge to advocate successfully with families and organisations for greater public investment in public services, in particular: **accessible public toilets**.

**Nowhere To Go (NTG)** is a partnership, which began in 2017, between Carers Northumberland, McLaughlin, Professor Derek Bell (Newcastle University), other disability and carer organisations such as Disability North, Newcastle Disability Forum, Age UK, and more recently Northumberland County Council and Newcastle City Council. McLaughlin was asked to become involved due to her research with families with disabled children highlighting the impacts of limitations in public services **[PUB 2]**. The team began their work by consulting carers and disabled people about what they believed were the greatest contributors to their social exclusion. Resoundingly what people said was that the lack of public toilets and the poor accessibility of those that remained was a key reason they did not leave the house. Parents of disabled children in those discussions and in McLaughlin's previous research spoke of changing children on the dirty floors of public toilets and of their battles with schools to adequately support their child's toilet needs **[PUB 2]**. Local authorities have no statutory obligation to provide public toilets, and this has meant their availability and upkeep has been one of the main casualties of welfare austerity. For example, Newcastle City Council provides no stand-alone public toilets, relying instead on toilets provided in commercial, leisure and community spaces. [Kings Fund Research](#) found that local authority spending on public toilets had declined 50% between 2009 and 2019. Working with carer and disability organisations and with carers and disabled people, NTG have responded by producing a range of resources informed by McLaughlin's research on embodied stigma **[PUB 5]**. The resources highlight the need to talk about and understand disabled people's different toilet needs and to advocate for change in local authority policy. Alongside film and [online](#) awareness raising material generating greater understanding of what the issues are, one very practical resource is the *How to Improve the Accessibility of Public and Customer Toilets Guide*. NTG ran a number of workshops between 2017 and 2019 that brought local government (county, city and town and parish councils), tourism agencies and disability and carer organisations together to inform the development of the resources and then to begin to shape policy and service provision amongst the local government actors and agencies.

Across council policy makers, advocacy organisations and disabled people and carers, the feedback has been that NTG has improved policy processes by creating spaces for voices to be heard, knowledge exchange to happen, for new partnerships to emerge and transformations in

thinking to occur. A Town and Parish Councillor after a workshop in 2018 to launch the Guide and other resources confirmed that she would *'discuss with my fellow parish councillors how we can support the provision of accessibility of different types of toilet provision'* and that she would *'plan in the budget for future provision of accessible and appropriate toilets... include all stakeholders particularly in new developments'* [IMP 1]. The current CEO of Carers Northumberland in local press coverage of the launch of the guide explained *'Carers have been instrumental in shaping the direction of the research carried out by Newcastle University and are buoyed that their experiences and suggestions have been considered for the implementation of the guide'* [IMP 2]. A parent of a disabled young person echoed this when she voluntarily contacted NTG to say: *'This was a project I am proud to have been involved with and the guide is excellent. I appreciate the amendments you made at my request for my own story'* [IMP 3]. The previous CEO of Carers Northumberland and now Head of Network Support in the Carers Trust explained that the benefit of working with NTG for them was that: *'While we knew about all these issues anecdotally, what we didn't have was access to research or resources that captured the experiences of carers and the people they care for, nor used their knowledge and experience to advocate for change'* and that working with NTG *'has helped Carers Northumberland build working relationships with other groups in our region and crucially a closer ongoing dialogue with the Council'* [IMP 4]. The Head of Neighbourhood Services at Northumberland County Council noted that NTG: *'gave policy and decision makers the opportunity to discuss individual needs with carers and individuals with disabilities, this fundamentally shifted my perspective and resulted in me considering the toileting needs of disabled people in every conversation I had about public conveniences thereafter'* [IMP 5]. After a knowledge exchange seminar in 2019 where McLaughlin, along with Carers Northumberland and Northumberland County Council discussed their collective activities, an AHRC Strategy and Development Manager who had been present got in touch with McLaughlin to say: *'I was so impressed by the rigour and sensitivity of the team, and I thought it was an excellent example of researchers engaging with local policy-makers and providing a bridge between the Council and service users' experiences'* [IMP 6].

NTG is also having a concrete influence on policy and practice to improve access to the public sphere and reduce social exclusion by raising the number and quality of public toilets in the region. Due to the precarious financial situation of local third sector organisations who work with disabled people and families, the focus of the *How to Improve the Accessibility of Public and Customer Toilets Guide* is on low-cost design changes that such organisations could implement, enabling them to increase the accessibility of their toilets for their users with complex needs. This means that community organisations in areas where families are affected by significant health inequalities can implement recommendations. For example, the Meadow Well Community Organisation in North Shields used the Guide to review and update their toilet provision and training of staff and volunteers. Their Chief Officer explained: *'As Chief Officer of a local charity, it is an absolute priority to make funds go as far as possible to meet the needs of our local residents where disability and health inequalities mean they live around 11 years less than those living just 2 miles away in St Mary's ward. The research pointed us to easy and inexpensive ways to ensure that our toilets were properly signposted and accessible to those with hidden disabilities as well as those with visible needs'* [IMP 7].

The Guide, and the knowledge gained by working with NTG and its disability and carer organisation partners, are now changing the policies and service provision of Newcastle City Council and Northumberland County Council. This is leading to improvements in the availability and accessibility of toilets in the region. Newcastle City Council is working with NTG as part of their goal to make the city Dementia Friendly. Engaging with NTG raised their awareness of the difficulties created for those with Dementia and their families by poor toilet availability and design. As a direct result of the NTG work with the Council, the Newcastle Labour Party now has a manifesto commitment to develop partnerships with others to improve the quality of accessible toilets provided by organisations such as shopping centres, leisure centres and community organisations [IMP 8]. The Cabinet Member for Health and Social Care confirmed with us that: *'I just wanted to let you know that at our manifesto planning session this week, we agreed to reaffirm our commitment to working with partners to provide and improve availability of*



*accessible toilets and changing facilities in the city. As you know, as a result of our [NTG] meetings and joint work... my fellow councillors and wider party members were pleased to hear about the progress we have made with this practical example of making the city inclusive and welcoming to all' [IMP 9].* Prior to the first Covid-19 lockdown, NTG were advising Newcastle City Council on improving the accessibility of toilets provided within the Grainger Market, a market used by older people from economically deprived areas of the city. While this work has been paused due to Covid-19, NTG are providing advice to the Council on the need to factor accessible toilet issues and needs into the changes happening in the city due to the pandemic.

On the 7 July 2020 (delayed due to Covid-19), Northumberland County Council Cabinet approved a new policy that directs GBP300,000 of capital spend to improve accessible public toilet provision [IMP 10]. This funding will be used to completely refurbish public toilets - including the provision of Changing Places toilets - in two of the largest tourist areas in the region: Lindisfarne and Seahouses. The case for funding drew directly from NTG recommendations in the *How to Improve the Accessibility of Public and Customer Toilets Guide* and the case made in the Guide that improved toilet provision would be an asset to the tourist industry. Northumberland County Council's Head of Neighbourhood Services acknowledged the importance of the work with NTG, saying that NTG '*directly influenced activities we have undertaken and funding decisions on local services that have been made,*' and that '*[i]ts grounding in Professor McLaughlin's long-term research on disability and family life gave us the confidence to make use of their findings'* [IMP 5]. NTG are working with the Council on the refurbishment plans, including leading on consultations with users (delayed by Covid-19) and plans for further significant investment (GBP1,000,000) within the medium-term budget planning cycle for 2021-2024.

In sum, McLaughlin's work in the North East supports individual and collective advocacy, user organisation and policy maker knowledge exchange and efforts to improve important aspects of public services. As a consequence this will lead to important changes in the ability to participate in life outside the home for the people and families she has worked with.

##### **5. Sources to corroborate the impact**

[IMP 1] Workshop (10 December 2018) evaluation of Town and Parish Councillor (pg 33-34) indicating the changes they would enact due to workshop and the launch of the guide.

[IMP 2] Northumberland Gazette article (3 January 2019) covering the launch of *How to Improve the Accessibility of Public and Customer Toilets Guide*, CEO of Carers Northumberland explains the importance of being involved in producing the guide for carers.

[IMP 3] 27 September 2019 email from NTG participant explaining what being involved in NTG meant to her.

[IMP 4] Testimonial from Head of Network Support, Carers Trust about their work with us when CEO of Carers Northumberland.

[IMP 5] Testimonial from Head of Neighbourhood Services, Northumberland County Council indicating the changes they have made due to working with NTG, in particular its role in the decision to invest GBP300,000 in refurbishments of public toilets.

[IMP 6] 9 May 2019 email from AHRC Strategy and Development Manager acknowledging NTG's ability to bridge the gaps between policy makers and user organisations.

[IMP 7] Testimonial of Chief Officer of Meadow Well Connected Community Organisation describing their use of the recommendations of the NTG Guide to accessible design.

[IMP 8] [Ambition For the Many Not the Few. Newcastle Labour Party Manifesto 2019](https://www.newcastlelabour.org.uk/wp-content/uploads/sites/331/2019/04/Newcastle-Labour-Manifesto-2019.pdf), which makes a commitment to expanding the provision and quality of accessible toilets in the city (pg 15). <https://www.newcastlelabour.org.uk/wp-content/uploads/sites/331/2019/04/Newcastle-Labour-Manifesto-2019.pdf>

[IMP 9] 31 January 2020 Email from Newcastle City Council Lead on Social Care confirming the inclusion of accessible toilets in the Manifesto was due to the work with NTG.

[IMP 10] [Summary of New Capital Proposals considered by Officer Capital Strategy Group](#), approved by the 7 July 2020 Meeting of the Northumberland County Council Cabinet.