

Dear Sir/Madam,

Letter of Support for New Zealand Changing Places Toilets - Director - Jenn Hooper

PAMIS (Promoting a More Inclusive Society) is a Scottish based charity dedicated solely to supporting people with profound learning and multiple disabilities and their families to lead healthy, valued and included lives. PAMIS are also the co-founders and co-chairs of the UK Changing Places Toilet Consortium and the lead organisation in Scotland supporting the development of Changing Places toilets.

Across the world there are millions of people who cannot use standard accessible toilets as they do not meet their needs. They require Changing Places toilets which are larger in size to allow for the user, often with larger wheel or powered chairs and their carer/family supporters, as well as room for siblings who cannot be left outside the toilet. They provide additional equipment such as a height adjustable changing bench, a ceiling track hoist and a peninsular toilet. Without these toilets, people cannot have their personal care needs met safely and with respect and are excluded from their community and enjoying day to day activities many of us take for granted. Users of Changing Places toilets include:

- people with profound and multiple learning disabilities
- older people, including people with Dementia and Alzheimer's
- people with muscular dystrophy and neuromuscular conditions
- people with cerebral palsy
- people with an acquired brain injury
- people with Multiple Sclerosis
- people with Spina Bifida
- people with Motor Neurone Disease

In Scotland the campaign to provide these facilities has been running for over 17 years and we now have Building Regulations that ensure all larger public spaces have these included. In reality many smaller venues and facilities are also now providing them. The rest of the UK are shortly to follow recognising the UN Convention on the Rights of Persons with Disabilities (UNCPRD) where it is accepted and expected that everyone has a right to live in the community, to move around within it and access all its facilities. The lack of a fully accessible toilet is denying people with more complex disabilities the right to be active citizens and to participate in their communities. This also has an impact on their families.

We were delighted when 3 years ago we were contacted by Jenn Hooper, a passionate mother with 3 children, one of whom has complex physical and learning disabilities. Jenn, like the family carers that we have spent 28 years working with, recognised that her daughter was missing out on many community activities because there was only one accessible bathroom where her daughter's personal care needs could be met safely and with dignity and this was at home. The only other option would be to lay her daughter out on a dirty toilet floor or in the back of a car. Jenn like all parents wanted all of her children to lead fulfilled and inclusive lives but recognised that a larger toilet facility with specialist equipment would be required. She reached out to Scotland to discuss her ideas for a New Zealand changing places toilet network where she as a family along with thousands of other families could begin to consider taking part in community based activities alongside others. We shared our experience and research on the size of the room that would enable all those who required the facility to access it. The floorplan of 4 metres by 3 metres accommodates even the largest of powered chairs and enables several carers to support the person

as well as accommodating single parents to have their other children in the same room while carrying out the personal care of their child with disabilities. Jenn as an experienced family carer understood all of this and was determined that not only would the toilets in New Zealand reach these standards but would exceed them.

Jenn has selflessly pioneered with this concept in New Zealand providing compelling evidence and real life stories of why these facilities are so important. Her first changing places toilet was opened in Hamilton Gardens in 2018 through sheer grit and determination and considerable personal unpaid contributions. The standards for total inclusion and attention to details are challenging the rest of the world to reconsider technology and specialist equipment to ensure that our changing places toilets meet the exceptional designs that Jenn has adopted. She is a family carer with years of experience in supporting a child with exceptional health and physical care needs. She knows first-hand what equipment will and won't work and she has also invested in working with other families to understand how they might want to use the facilities across New Zealand. This is not a business this is a way of inclusive life for her and her family and for the thousands of currently excluded people within the communities of New Zealand and indeed across the world.

Scotland and the UK Changing places toilet consortium are in regular dialogue with Jenn and are keen to pursue some of the recent innovations within her design, particularly the access system. We have been in discussion with Jenn regarding the setting up of a world collaborative ensuring that the standards being set in New Zealand are not diluted elsewhere. Our common vision is that no matter where in the world you go you will have access to changing places toilets that are of a standard that enable all users to access and use them. Jenn will be a key player in taking this vision forward.

In our experience of over 17 years of campaigning and supporting the development of this resource we know that the most influential and knowledgeable about requirements are the family carers themselves. Our organisation is led by the families' we support who are experts in the care of their loved one. Their caring role is often 24/7 and for the life span of their child. Jenn is an advocate for these family carers but also for her daughter and all those that need this facility. However Jenn has also noted the wider population of people with complex disabilities who may require Changing Places Toilets Her designs and ideas are creative, innovative and practical and cater for the larger wheelchairs, the additional number of carers and the complexities of care equipment required across a spectrum of disorders. This contribution and selfless commitment to setting up a network of facilities across New Zealand should be applauded but also supported. Her unique contributions within New Zealand are well researched and are leading the way for inclusive design not only in her home country but also supporting many of us in other countries to rethink some of our designs. Again our experience in Scotland tells us that working with well-informed family carers like Jenn means that the right design, equipment and practical solutions will be developed that support the issues people with complex disabilities and their families face.

We, in the UK Consortium, have learnt from Jenn, her experience, her designs and ideas and we will continue to work with her as we move into a future world collaboration. Family carers like Jenn, and people with disabilities themselves, must lead on this because their vested interest is not in profit and business but seeped in human rights, care and compassion not only for their children but for the millions of other disabled people who require support to be a part of their communities.

Yours faithfully

Jenny

Jenny Miller, Chief Executive | PAMIS | Co-Chair Changing Places Toilet Consortium

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