INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Name: Mrs Jane Balke Andersen

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To the committee,

I have been incapacitated in some way since 1993. I survived on a Disability pension and my family caring for me. I moved to NSW in 2011 to live with my partner, now husband. Since becoming so disabled in the last few years that I can no longer function "normally", my life has become 4 walls and a bed. We began trying to get some help and were shunted from one agency to another. No one had any funding to help us, no one could help under 65 years of age, everyone told us to get NDIS funding. We applied, waited and were rejected. I didn't fall into a simple to understand category. Then someone helped us reapply so we could show that no treatment works and there's is no treatment I have not tried. We are still in limbo waiting to hear the outcome of that application. The whole process began in early 2017. And still we wait. Meanwhile my husband struggles along by himself trying to do everything: cooking, cleaning, washing, helping me walk, shower, dress and do anything I need. We can not afford to buy mobility equipment, respite care, house cleaning, let alone any positive things to improve my life. Or make his more bearable. We received 1 hour a fortnight subsidised house cleaning from Benevolent for a few months, but that too has been taken away because I am not over 65. We began fundraising for a new wheelchair in 2017, months later we still didn't have enough. Recently Enable NSW has helped us with a wheelchair, shower stool, commode and walker. These pieces of equipment have helped get me from bed to toilet or out to a taxi to get to the doctor or hospital. This is basic mobility equipment, everyone who can't walk should have access to a wheelchair! We went without for months. We are left in limbo, forgotten and ignored while the NDIS fails. The government fails to fill in the cracks. If I could get better, I would. No one wants this life. Isolated, in pain, dependant on one person for everything. My husband slowly gets more tired, less healthy and I watch him becoming a different man trying to cope with being everything. And we do it on our Disability Pension and Carers Pension. The government says every Australian counts, but what they should say is "Every healthy ABLE-BODIED Australian counts." This situation has driven me to thoughts of suicide. I fight my illness, my depression, my situation and the government to treat me with some humanity. As time passes and things become more desperate, it's hard to see any future. Is this what we choose for our fellow Australians? How we treat those least able to care for themselves shows who we really are. So far it's not a pretty sight. And still we wait.

Jane Balke Andersen

, NSW June 2017