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

Name: Name suppressed

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Partially Confidential

Submission to the Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in NSW

NSW Parliament

To whom it may concern,

I am an Australian tax-payer, an NSW resident. I have a chronic illness — but am in remission of symptoms at this point, early stages of the disease. I am the sister and sometimes carer and a core support person with multiple complex disability after acquiring a head injury as a child. (Brain injury after being hit by a car on a NSW road.) He has been rehabilitated on going since the mid 90s and has benefited for many fantastic disability services offered by the NSW government since then. His high quality of life since the accident is directly connected to these services & people and the on going support they have offered my parents as full time carers. (Including essential respite services) He is an actor, singer and performer. Has performed at NIDA & Sydney Opera House and continues to be productive, ambitious and a contributor to NSW society.

Our experience (being both my parents & myself) as advocates for my brother to get onto the NDIS, has been a difficult one. Negotiating the NDIS was cumbersome, disorganised, confusing and belittling. 'We got there' in the end. Processes of access are flawed in many ways. The scheme does not capture ALL considerations & situations of people living with a spectrum of disability (and their core supports – aka family & friends) I believe the NDIS processes have along way to go to become practical, and complimentary to peoples lives. The NDIS is NOT a replacement for the Disability & Aged care services – namely 'inbetweener' medical services. No other state has dismantled these services – as they are core essential services for our countries most vulnerable and at risk people. People that so dearly NEED and WISH and CAN and ARE be part of this civil society.

I was told out right that people 'will fall through the cracks' at a NDIS information session last year conducted by the Department of ADHC, before the NSW rollout. **Absolute shame.** How dare the NDIS be rolled out, with NO PLAN for these at risk people. I ask you reading this, if one of those people were a father, a sister, a partner – if you would want to know – WHERE these people will fall? On/into an already stressed NSW hospital system? It is not a solution for those 'inbetweeners' to live in hospitals for months on end, with no solution. I want this inquiry to address the qualitative data (people's stories) coming through about

these instances and death and mistreatment that has come to light in the transitions for particularly high needs folk – from state to private care.

Many existing NSW disability advocacy groups have helped my family along the way — and we need to rely on these resources in the future. It is a multifaceted approach we need to disability services and *STATE AND PRIVATE* industry to suit the multifaceted nature of individuals who are relying on the state to assist in their empowerment - to contribute to society. To exist happily, productively and healthily. They have a UN identified right to these things, and so the responsibility falls on the Federal & State to address and provide.

This inquiry – must address the gaps between the NDIS & State responsibility and re instate the Department of ADHC as soon as possible. This time will be looked back on an a serious breach of human rights and much harm right now, is coming to families, carers & those working on the system trying to make it work.

This is urgent.

Listen deeply and effectively to the concerns of your NSW patrons, and please act immediately.

Sincerely,