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Media Release

“We don’t want Jacob dying of discrimination” – politicians called on to end deadly disability discrimination

The first time Jacob was refused treatment was when he was 15 years old. A nurse refused to treat him as she did not see the point in saving him. Since then his mother, Linda, has had a number of bad experiences with both doctors and nurses failing to give him the treatment he needed and making it clear that they thought it would be better to let him die.

Each time Linda Hughes takes her son to hospital she doesn’t know if he will be treated with discrimination or not. Jacob is now 29 years old. He has developmental disabilities and does not communicate with words.

“When Jacob has to go to hospital we just don’t know who is going to be there. We don’t know if they are going to have a bias against people with disability. They might be really unconscious about that bias. It is probably that they fear disability themselves and can’t imagine a person with disability having a good quality of life.”

“But we don’t want Jacob dying of discrimination.”

The statistics are shocking. Up to half the deaths of people with intellectual health are preventable and people with intellectual disability are dying up to 27 years earlier than most people.*

At this upcoming federal election Council for Intellectual Disability and Inclusion Australia with their partners are leading a call for this deadly disability discrimination in our health system to be addressed and for political parties to implement the [National Roadmap for Improving the Health of People with Intellectual Disability](#)

The Roadmap, developed by the Commonwealth Department of Health with the disability and health sectors, was launched by Health Minister Greg Hunt in August 2021. It is a 10 year plan to improve the health of people with intellectual disability. It will build broader capacity in healthcare; give health care professionals the knowledge, skills and right attitudes to provide quality, appropriate and disability-informed health care and create the National Centre of Excellence in Intellectual Disability Health.

“We need to address the terrible health inequalities people with intellectual disability face – implementing the Roadmap and the Centre of Excellence are essential if we are going to make change.” said Jim Simpson CID Senior Advocate

“With all the uncertainty that an election brings, we need to have full buy in on the Roadmap and the Centre of Excellence from key political parties and independents contesting this election and we need the Government to fund the National Roadmap in their upcoming 29 March Budget.”

An **Open Letter** (attached) signed by well over 100 academics, CEOs and eminent persons has been sent to the Minister for Health, Greg Hunt and the Shadow Minister for Health, Mark Butler calling for political parties to implement the Roadmap and fund the Centre of Excellence. Signatories include Dylan Alcott, Australian of the Year 2022, Graeme Innes (former Disability Discrimination Commissioner), Robyn Kruk (former CEO of NSW and Commonwealth health agencies), Eileen Baldry (Deputy Vice Chancellor UNSW Sydney) and numerous distinguished doctors and health professionals.

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Media Contact: Rochelle Porteous 0404 487 247

Available for interview:

Jim Simpson CID Senior Advocate

Professor Julian Trollor, Director, Department of Developmental Disability Neuropsychiatry, UNSW Sydney.

The link to the video of Linda and Jacob is here: <https://youtu.be/nIN0QCGtVo8>

*** References:**

[Health Status of People with Intellectual Disability Evidence Summary 22 June 2021](#) Trollor, J (2021)

[Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data](#), Trollor, J; Strsuebku, P, Han Xu and Howlett, S (2017)

[Upholding the right to life and health: a review of the deaths in care of people with disability in Queensland](#), Office of the Public Advocate (Qld) (2016)

