

Media release - 22 June 2020

## **National networks call for ‘disability’ recommendations to be ignored by Government**

The Family Leadership Alliance contests that while the Health and Disability System Review may have good ideas for the “health” system, it is way off the mark with many of its comments related to the disability support system. At best, many of the thoughts expressed in the report are a remnant of 1990s thinking when it comes to disability.

Tony Paine states, “While we support the aims of the review to help improve and simplify access to the Health and Disability system we are deeply concerned that the recommendations – especially the move of disability support to DHBs - will lead to increased bureaucracy and medical control of disability. This is the complete opposite of decades of work by disabled people and their families to get more control over their lives and the support they might need, and more independence from intrusive systems and decision-making.”

“Many of the recommendations in the report, related to the disability system, do not come from our community and they are not supported by the community. The report is a dangerous diversion and would potentially erode a massive amount of work done by disabled people, families, providers and officials after the 2008 Select Committee Inquiry”, states Mark Benjamin.

Jane Bawden states, “The Health and Disability System Review Report misses the mark for disabled people and whānau. Over the last decade consumer led responses, including disabled people and whānau together, have put the consumer at the centre of decision making in the EGL pilots and in personal budget holding initiatives. The report seems to suggest a return to doing “to” and “about” the person and whānau”

The Family Leadership Alliance endorse the initiatives of the last two Governments to transform the disability support system. We are calling for the Government to disregard many of the erroneous recommendations in the report, related to the disability support system, and continue to work with disabled people, families and innovative providers to make it easier for disabled people to create good lives for themselves.

Jane Bawden states “Disabled people and whānau are the experts on their own lives. Systems should serve us in the way that we determine is appropriate for us. We are well beyond a consultation and representation model now and it would be a retrograde step to go backwards. We look forward to the health sector catching up. Unfortunately, the review panel did not include disability lived experience and the lack of understanding is evident in the recommendations”.

With the Enabling Good Lives vision and principles as a foundation, we are moving towards disabled people and whānau being self-determining, having more authority and interacting with systems that are easier to use. There is momentum for positive change. Too many people rely on current work being advanced. We are calling on the Government to both affirm current progress by disregarding many of the recommendations in the report that relate to the disability system and prioritise investment in system transformation developed by disabled people, their whānau and their allies.

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The Family Leadership Alliance is a collaboration between Parent to Parent New Zealand, Imagine Better and SAMS. These organisations all have national networks and equip families and whānau with the information, connections, skills and roles to effect positive change at a personal, whānau, regional and national level.

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