



8 May 2022

Mr Adam Bandt
Leader of the Australian Greens
Member for Melbourne

Senator Jordon Steele-John
Senator for Western Australia
Australian Greens spokesperson on health and disability services

Via email: [REDACTED]

Dear Mr Bandt and Senator Steele-John

REQUEST FOR GREENS COMMITMENT TO SOCIAL SECTOR REFORMS THIS ELECTION

Better Access Australia is writing to seek the Australian Greens commitment to our recommended key actions and reforms of our social sector as part of your 2022 federal election policy platform.

We acknowledge the Australian Greens strong and clear policies on health and the NDIS and consider many of our requests align with the philosophies of access, equality and responsibility articulated by your party during this campaigning period.

Our request builds on our work [REDACTED] to end the discrimination against members of the community accessing the Opioid Dependence Treatment Program (ODTP).

WHO ARE BETTER ACCESS AUSTRALIA

Better Access Australia was established to advance improvements in health, disability, and social services for all Australians by 2030. We contribute to the public policy debate in Australia through research, publications, public discussion and advocacy.

Better Access Australia do not advocate for specific diseases, medicines, diagnostics or individuals. We advocate for system-level reform that allows all to benefit – consumers, service providers and government.

We believe the foundations of our social sector are solid and deliver reasonable services to many Australians. However, significant challenges and opportunities remain. Australia's governments, industry and not-for-profit sectors need quality advice and strong advocacy if they are to be responsive and agile in addressing the policy reforms necessary to keep pace or surpass international best practice by 2030.

WHAT COMMITMENTS WE ARE ASKING FOR IN THE FEDERAL ELECTION

Better Access Australia is calling on all parties and independent candidates to **#MINDTHEGAP** in affordability and access to health care and the national disability insurance scheme (NDIS).

For healthcare it's the gap in affordability of time to access, and the gap in the financial affordability that care. Patients can afford neither the time delays nor the increasing out of pocket costs.

Building on the bi-partisan findings of the [parliamentary inquiry into access to novel technologies](#) on affordability of healthcare, *Better Access Australia* is seeking election commitments to reforms that reflect areas of high need and where Australia has fallen woefully behind global standards let alone global better practice in its administration of our healthcare system.

For the NDIS it's about addressing the growing complexity, inconsistency and gaps between the processes, services and support provide to the community in accessing the health system, the NDIS and employment opportunities. It's about improving transparency in decision-making in the bureaucracy in an effort to end discrimination and inconsistent access and insufficient empowerment of the people the social sector is supposed to serve.

The six election commitment reforms we are asking for are a combination of targeted reforms for some of the most vulnerable in our community as well as system-wide reforms to benefit a broader population.

1. *#MindtheGap in newborn screening*
with a nationally funded newborn screening program for 80 rare diseases
2. *#MindtheGap in keeping healthcare affordable for patients*
with a mid-tier PBS co-pay of \$20 and freeze indexation increases for five years
3. *#MindtheGap in time to health technology access*
with a #100day from TGA registration to subsidised system access KPI
4. *#MindtheGap in the affordability of private healthcare*
with a review that addresses consumer needs and out of pocket costs
5. *#MindtheGap in government mandated discrimination*
by ensuring all PBS medicines are protected by co-pays and safety net
6. *#MindtheGap in access between health, NDIS and employment support*
by improving assessment processes and equality of access

Full [details on these measures](#) are attached to this letter. However, on the issues of newborn screening and PBS affordability we provide the following additional information for your consideration noting that Labor and the Coalition have made statements of commitment on these reform requests.

NEWBORN BLOODSPOT SCREENING

This weekend we had two further stories in the media of families who had lost a child due to inadequate newborn bloodspot screening, and those whose baby had been saved from a pilot program. There have been over 20 such stories in the past year, all with the same themes. ⁱ ⁱⁱ Treatments are available, testing is available, but Australia doesn't screen, or a state or territory doesn't screen and so our children suffer.

Labor has committed to our call for a national takeover of newborn screening and immediate expansion from 25 to 80 diseases, with bi-annual reviews thereafter to ensure we never fall so behind again, and ensure we keep pace with changing work in genomics screening opportunities. After 30 years of inaction, we are incredibly grateful not only their commitment to make this change if elected, but their demand this morning that the Coalition stop politicising babies and join them in bi-partisan support for this measure.

Without diagnosis there is no treatment, no clinical trials, no access to the NDIS, no access to health support services. Each day 5 babies are missing out on an urgent diagnosis that could prevent irreparable damage, including loss of life. That's 5 babies today. 25 this week, 210 babies this election period, over 1800 babies every year missing out on diagnosis, treatment and care.

We are asking the Australian Greens to make the care of our newborns a national health priority once again and commit to a national and expanded newborn bloodspot screening program. Let's bring this 1990s approach to healthcare into 2022.

AFFORDABILITY OF MEDICINES ACCESS ON THE PHARMACEUTICAL BENEFITS SCHEME

Better Access Australia has publicly welcomed both major parties' recognition of the increasing cost of living pressures and daily unaffordability of medicines, with commitments to reduce the general PBS co-payment from \$42.50 to \$30-\$32.50 on 1 January 2023.

Better health, disability and social services

betteraccessaustralia.org.au

BAA's election commitment is broader and requests the freezing of indexation until our economy is less volatile for working families, and support for a means-tested access to a \$20 co-payment to ensure those that can afford to pay, do, to make funds available for those that cannot.

Whilst this is important to us, our even greater concern is the inequality of access to the PBS co-payments and safety nets imposed on those accessing treatments for opioid dependence.

Neither the 2022-23 Budget's safety-net measure, nor the major party commitments to reduced co-pays will help these 53,000 patients as the department continues to deprive them of the protections of the *National Health Act*. A removal of protections the Parliament considers a court would find unlawful.

Rather than redress this discrimination against those with a recognised disability under the *Anti-Discrimination Act* as first raised by Senator Siewert, then the Senate Delegated Legislation Committee and then Senator Steele John, the Minister Hunt simply commissioned a post-market review which is now in its 14th month.

We need to end the discrimination against a disease that is taking 3 lives everyday. These are some of the most stigmatised people in our community. We have to make these policy commitments of cheaper co-pays and safety nets available to all patients, no exceptions. We would not tolerate this for any other disease

BAA is asking for immediate inclusion of opioid dependence treatments in safety net calculations and PBS co-payment application

These safety net and co-payment reforms will be one of the first pieces of legislation introduced into the new parliament.

We are asking the Australian Greens and all independent candidates to ensure the Bills are sent to a proper committee review (unlike the increasing costs of medicines bill last year). This will provide an opportunity to demand protections for ODTP patients as well as better consumer and patient-centric development of the national medicines policy, HTA review and setting new KPIs for access such as 100days from TGA registration to medicine, medical device and pathology testing subsidies.

We hope you will review our other policies and public statements about our emerging concerns with the social services sector these past 18 months.

As always, we thank you for all your work and interest in 2019-2021 in the inequality of the ODTP and hope you will consider supporting our calls for change to rectify all these gaps in our health and social services sectors.

If there is any further information or assistance we can provide to enable the Australian Greens to commit to these reforms, we would welcome the opportunity to do so. Please do not hesitate to contact [REDACTED]

We look forward to your commitment to these measures.

Yours sincerely,

Felicity McNeill PSM
Board Chair

Helen Innes
Board Member

David Mackay
Board Member

ⁱ Sue Dunlevy, '[babies dying of SMA because governments won't spend \\$10 on test](#)' Daily Telegraph 7 May 2022

ⁱⁱ Jane Hansen, '[bubble boy hugo saved by new blood test](#)' Daily Telegraph 8 May 2022