Select Committee on Cost of Living
PO Box 6100
Parliament House
Canberra ACT 2600

28 March 2024

To whom it may concern,

The ANU Disability Justice Research Hub (DJRH) values the opportunity to present our submissions to the Select Committee on Cost of Living. The DJRH is a recently formed undergraduate research initiative under the Law Reform and Social Justice (LRSJ) at the Australian National University College of Law. The DJRH is comprised of both able-bodied and disabled students, who have a keen interest in identifying barriers faced by people with disabilities (PWD) and advocating for the inclusion and empowerment of PWD in Australian Society.

This submission is based on pre-existing research and the knowledge shared amongst community stakeholders. PWD are particularly sensitive to the downward trends in the economy and have a higher cost of living compared to their able-bodied peers. This submission is important to the disabled community, as their voices are often ignored in discussions of policy. There is an ignorance regarding the experiences of PWD in everyday life. The way the disabled navigate society is more complex, and there is an attached cost to engaging with the public. The levels of additional costs imposed on PWD, a group more likely to be low-income, is incredibly isolating. The voices of PWD cannot be ignored in this discussion, and we believe that the Federal Government has a duty to listen to their experiences.

Our Submission will address reference A, B and D. We have provided a summary of our submissions below and elaborate on them relating to the terms of references. We welcome the opportunity to answer any questions in relation to our submissions. We can be contacted at: lrsj@anu.edu.au.

Kind regards

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Summary of Submissions

Submission 1: Disabled Australians earn less than the able-bodied counterparts. This makes PWD far more susceptible to poverty, particularly when the economy experiences a downturn.

Submission 2: Since PWD have a higher level of engagement with the healthcare system, they face far-greater cost when accessing necessary healthcare such as GP visits and Pharmaceuticals.

Submission 3: The higher burden of cost faced by PWD is exacerbated by the lack of regulation in price-setting by medical professionals.

Submission 1:

About four million people in Australia have some form of disability, of whom 2.1 million are of working age. An Australian study showed that the costs of disability in households with at least one family member with a disability was 37% of the disposable income. This means that households with people with a disability (PWD) need to increase disposable income by 37% to have the same living standard as those without a disability (Vu, et al., 2020). PWD face a range of challenges seeking and progressing at work, including attitudinal, informational, physical, and systemic barriers. Australian Bureau of Statistics (ABS) data shows that:

1. of the 2.1 million PWD of working age, just over half (53.4%) are in the labour force, compared to 84.1% of those without disability.
2. The median gross personal income of PWD is less than half that of people without disability; and
3. Australians with a disability are also less likely to be employed full-time (27%) compared with those without a disability (53.8%) (Australian Bureau of Statistics, 2020).

There are several ways to explain these statistics. Employment discrimination against PWD is ongoing and systemic. Discrimination can enter at any point of the employment cycle, from recruitment onwards, with severe consequences to social and financial wellbeing. Women with disabilities face compounding discrimination in the biases in the workplace. They have lower workforce participation rates; are more likely to work in informal, vulnerable, part-time, and lower-paid jobs; are less likely to be in paid workforce; and have lower incomes than men with disabilities (Workplace Gender Equality Agency, 2024). Furthermore, PWD generally have a lower level of personal income than people without disability. Even having one PWD living in the household is also associated with lower levels of household income. ABS data shows that that 38% of PWD's weekly income can be classified as low income, compared to 27% of able-bodied Australians. The data collected also confirmed that only 20% of PWD reported their income was within the high-income bracket, compared to 37% of able-bodied Australians (Australian Bureau of Statistics, 2020). It can be seen from the above data that PWD tend to be worse off financially than those without disability. This can affect their ability to raise funds in an emergency, pay bills or buy food. Some PWD seek help from friends, family, or welfare and community organisations because of financial problems. Given the precarious financial situation PWD face in the good times, the impact of an economic downfall is particularly severe and can push them towards poverty.

Generally, for PWD aged 15–64:

1. 38% describe their level of prosperity as just getting along, and a further 8.7% describe it as poor or very poor. This is compared with 24% and 2.2%, respectively, for people without disability.
2. 42% are not satisfied with their financial situation, while only 24% without disability report the same dissatisfaction.
3. 55% would not be able to easily raise $3,000 in an emergency, compared to 41% without disability); and
4. 20% have experienced financial stress in the current year, while only 8.8% without disability report financial stress (The Australian Institute of Health and Welfare, 2022).

Australia has one of the lowest employment participation rates for PWD in the OECD, but it should be noted that we don't treat all disabilities equally. The employment participation rate is even lower for people with an intellectual disability. Only 39% of people with an intellectual disability are in the labour force. This is a concerning percentage as people with an intellectual disability are much less likely to have full-time work. More than 20,000 PWD, most of whom have an intellectual disability, are employed in around 600 Australian Disability Enterprises (ADE) across Australia. An ADE is employment support for PWD who need significant support to work. While open employment is open to everyone, most people with intellectual disability are employed in closed employment, like ADEs. Currently, ADEs pay as little as $2.36 per hour for work under the Supported Wage System and $3.50 per hour under the Fair Work Commission findings. The fact we allow disabled people to be paid at such a low rate is compounding on the financial hardships they already face by being barred by most employment (Inclusion Australia, 2022). The Australian Bureau of Statistics revealed that people with an intellectual disability were less likely to be employed full-time (12%) than people with other types of disabilities (32%) and the population without disability (55%). Further, around 34% of people with an intellectual disability found it difficult changing jobs or getting a preferred job, and about 38% felt they were restricted in the type of job they could get (Australian Bureau of Statistics, 2020).

In times of an economic downfall the above numbers can only get worse. If a PWD loses their job or if they didn't have one before, then they do not have a level playing field with their non-disabled neighbours. It takes longer, and is more difficult, for disabled workers to return to the labour market (Purton, 2009). Even before the COVID-19 pandemic, people of low socio–economic status, or struggling with existing debt, experiencing housing insecurity, labour market exclusion, and/or challenges in accessing health and social services before, now these individuals are at risk of further marginalisation and increased vulnerability to both physical and mental illness. This is particularly concerning for Australians with disability, who experience persistent socio-economic disparities and poorer employment outcomes than Australians without disability. In the emerging labour market, the risk of exclusion from decent work for many PWD will be exacerbated by poverty, discrimination, and health risks and is likely to be long-lasting (Olney, et al., 2022). Overall, it is obvious that the impact of an economic downturn on PWD is particularly severe, pushing them further towards poverty.

Submission 2:

Australia has a mixed healthcare system, which nowadays is consistently failing PWD. Medicare, Australia's universal public health insurance scheme, provides free public hospital care along with subsidised private hospital care, a range of services provided out-of-hospital and prescription medicines. In 2019-20, Australians spent an estimated $29.8 billion out-of-pocket (OOP) on health, including over $6 billion on Medicare-subsidised out-of-hospital services and prescription medicines. OOP costs for Medicare-subsidised out-of-hospital services and medicines cannot be claimed through private health insurance. The Medicare Benefits Schedule (MBS) lists the services covered by Medicare, including those provided by general (primary care) practitioners and specialist doctors. For out-of-hospital services, patients are free to choose their own doctor, but specialist services are only subsidised if they are referred by a general practitioner. The MBS lists a price signal (schedule fee) and the benefit amount (rebate) that it will provide (85–100% of the schedule fee). However, doctors are free to charge any price. Therefore, any excess fee charged above the benefit results in an OOP cost to the patient. Prescription medicines are also subsidised by Medicare through the Pharmaceutical Benefits Scheme (PBS), where patients pay OOP up to a maximum amount (co-payment) per medicine ($38.80 for general patients and $6.30 for concessional patients in 2017). Concession cards are available to pensioners and those receiving certain social security benefits, among other eligibility criteria (Di Law, et al., 2023). OOP fees are also part of cost-sharing measures between governments and patients, because of increasing government expenditure on health care and unprecedented levels of demand. Only 44% of private hospital admissions had no out-of-pocket fees in the 2020–21 financial year; and in the same period only 34% of specialist attendances were bulk billed (i.e. with no OOP fee). The average OOP fee for out-of-hospital specialist and obstetric services was $98 and $303 per non-bulk billed visit, respectively.

The Medicare safety net reimburses patients at a higher amount once they have reached a certain threshold of out-of-pocket expenditure in a year ($531.70 in March 2023). This is initially 85% for most out-of-hospital services, or 100% of GP services, increasing to 100% under the safety net. There are two issues with this system. First, patients are required to pay OOP for health care up until this point which can be difficult when a person lives pay-check to pay-check. Second, there is still a disconnect between the schedule fee and the fees charged by providers, leaving patients vulnerable to open-ended out-of-pocket fees. The extended Medicare safety net applies when a higher threshold in OOP has been reached. In March 2023, the threshold was $770 for people who have a concession card or family tax benefit, and $2414 for others. The extended safety net reimburses patients at 80% of out-of-pocket expenditure based on the actual provider fee. However, this extended safety net does not truly address the first problem associated with the safety net in general (Callander, 2023). These numbers have real world consequences. These costs add up and create economic hardship, and individuals do forgo care, with one in four Australians without a health care condition and up to one in two with certain health conditions avoiding care because of the cost. The amount paid by households on health care in Australia was estimated to be $3200 in 2014, with out-of-pocket fees per health care service rising over time (Callander, 2023). Although the private market is subsidised through Medicare, patients are only reimbursed a fixed amount based on the Medicare schedule fee for each service. This schedule fee generally does not cover the total cost of the service.

Not only are PWD faced with paying similar levels of out-of-pocket costs, but they are also faced with costs for care that exist outside of the publicly subsidised health system. There are limits to what is covered under different aspects of the safety net. Many aspects of community-based care are associated with part, or all the cost being borne by the patient, in many cases with no safety net provisions (for example: wound dressings, incontinence pads, community nursing and allied health visits). Those with chronic conditions and disability often rely on many services that are not covered by the MBS, which relies on them to either spend more of their limited income on a comprehensive private health insurance policy or to foot the bill themselves. Under certain GP plans, patients are entitled to 5 subsidised allied health visits per calendar year, but this is still inadequate to meet the needs of many disabled Australians. Furthermore, new unsubsidized treatments continue to become available. An ageing population, innovations (some with very marginal benefits) and the risk that some procedures are overused or harmful all contribute to unnecessary financial (and emotional) pressure on patients and their families. Procedures and interventions, at times with marginal health gains, are being promoted actively, frequently with high costs and little meaningful benefit in terms of quality of life or survival (Currow & Aranda, 2016). Complex chronic health conditions can be disabling and trying to access new treatments for them can be financially unviable, even when there is ample evidence they improve a person's quality of life. The government does not subsidise medical devices, blood, or blood products, over the counter or complementary medicines via the Pharmaceutical Benefits Scheme (PBS). Nor does the government subsidise the price of prescription medicines that are not available on the PBS or the Life Saving Drugs Program (LSDP) (providing the federal government's subsidy of high-cost transformational therapies for rare diseases through individual agreements with medicine sponsors). Pharmaceutical products that are registered on the Australian Register of Therapeutic Goods but not listed on the PBS may still be supplied in Australia on private script, and there is no restriction on the prices that may be charged by an Australian sponsor (Day, 2023). Furthermore, medicines can be listed under the PBS only for certain diagnostic criteria or medical conditions. When these medicines are prescribed "off-label" (for conditions that the medication isn't approved to treat, but there is evidence it has a therapeutic benefit), patients must pay for these medications privately. For those with rare or under-researched disabilities, this saddles a huge financial burden onto them. Medicines used to treat these conditions usually aren't covered under the PBS or are approved to treat that specific condition.

When combining all these costs with the fact that many PWD earn less, the results are sobering. For many PWD, delaying necessary care is not optional, and they rely on family, friends, or other sources of income to meet these costs. For others, they ration their medications or put off vital treatment to keep the heater on in Winter. For everyone, there is a calculation on which services are most important and what can be delayed being able to afford their necessities. The reality of living on a low-income means that there is a constant worry surrounding expenditure, and how you would be able to afford living. The authors of this submission think that this is unacceptable in a developed country like Australia. A simple solution to this would be to increase funding to the Medicare system. By matching the MBS fees with the real-world cost of providing services, it reduces the need for doctors to charge OOP fees and reduces the financial pressures on all Australians who need to interact with the healthcare system. This solution benefits everyone, but the relief will be extremely helpful for PWD, since they face a higher level of engagement, and therefore cost, with healthcare systems in Australia. This is money they can then spend in other areas of the economy, and this additional room in the budget will relieve the huge stress that is associated with financial hardship.

Submission 3:

Our intention with this submission is to draw attention to a major shortcoming in Australia's healthcare infrastructure: the unrestrained pricing and the general lack of regulation in the medical industry's pricing practices and their pronounced effects on persons with disabilities. The Australian healthcare system has consistently been ranked as one of the best on a global scale. However, hidden under this statistic is the fact that healthcare in Australia is becoming increasingly inaccessible and unaffordable, with the out-of-pocket spending averaging at 849 USD per capita (as of 2020), placing it at the highest end of the OECD average for what individuals from different countries are paying out-of-pocket for their healthcare. While these figures paint a bleak picture as is, the situation is worse by leaps and bounds for individuals with disabilities. Over 52% of PWD are unemployed and merely 8% of them receive the Disability Support Pension and work part time. (Figures as of 2018). Even amongst those fortunate enough to be employed, there exists a wage gap of over $500 AUD per week. This predicament is worsened by the fact that disabled people are also more frequently in contact with and often in greater need of the healthcare system, thus exacerbating the financial burden on an already vulnerable group. The increasing issue of price gouging by medical professionals and the lack of systemic regulations when it comes to regulating these obnoxious charges has further ensured that disabled people remain disproportionately penalized in a system that seems to be conveniently indifferent to their struggles. The healthcare system has thus morphed into an arena of extreme financial and emotional distress for PWDs, with more and more individuals choosing to either consciously not reach out for medical support when needed or are unable to. This is reflected in a statistic that reported that over 10% of PWDs that needed to go to a hospital reported an unmet need for hospital admission in 2018.

Healthcare in Australia operates as a free market but by no means is a fair one. The Medicare Benefits Schedule provides a schedule fee applicable for each service and the percentage (between 85% to 100%) of that schedule fee that will be rebated. Practitioners are however free to charge anything above the schedule fee, with the burden of covering this extra cost falling directly on the patient or on the patient's private insurance provider. Since what is charged is purely at the practitioner's discretion, it is not uncommon to see specialists charging more than double of what the schedule fee for a particular service is. The supposedly free public healthcare system has also truly taken a turn towards the absurd. Individuals with referrals from GPs are often not met with 1-year (and often more) long waitlists as one would expect, but with outright refusals. Individuals are therefore not just denied immediate care, they are often denied the very possibility of receiving care, effectively shutting them out of the system that was established with the intention of serving them. Patients are therefore left with no choice but to find solace in the hands of private practitioners if they wish to be treated sometime soon. Private practitioners and specialists owing to their high demand are thus free to charge notoriously high rates for their services, often leaving their patients out of pocket by thousands of dollars. One must also note that while the out-of-pocket spending has increased by over 50% between the years 2012-2022, there has been no such comparable upscaling of income, let alone in the income of PWD. Despite unregulated pricing being a typical characteristic of a free market, healthcare, or at least healthcare in Australia does not function as one in the sense that while price makers are free to decide their prices, the consumers certainly don't have the same freedom when it comes to choosing where to avail their services from. Comparing services and their prices and negotiating prices in the medical industry is a Herculean task given the lack of transparency prevalent in this field. Quotes for procedures are often provided to patients well after the consultation, with some charges like the anaesthetist's fees being unknown until after the booking has been made.

Another factor that contributes to the increasing uncertainty in the price of services is that new unsubsidized treatments have become available for a variety of chronic conditions (mostly seen in practices that treat cancer). Such novel (and often expensive) procedures are actively promoted, often providing very little improvement to the patient's quality of life. Financial disclosure in the Australian context thus not only refers to how much a procedure will cost, but also if there are any alternatives that offer similar benefits at a lower cost to the patient. This is especially important for dealing with patients from groups that are more prone to financial hardships (PWDs being one of five groups most prone to financial insecurity), in fact it might be as, if not more important than disclosing the side effects or potential medical risks of a medical procedure. A new standard for financial disclosure is the need of the hour - a standard that moves beyond disclosure of the costs of a single procedure to one that accounts for the costs of a full pathway of treatment and all the alternatives open to the patient. The issue of financial toxicity in Australian health care requires open debate and individual-level data on rapidly rising out-of-pocket costs, and advocacy that gives paramount importance to patient wellbeing. It is also crucial that there exists a system that can present to an individual data on the variations that exist in rates charged by identically credentialed practitioners offering identical services and the waiting times associated with these services. This data being provided transparently to the patients is what will transform Australia’s healthcare market to function as a truly free market, where the consumer has all the information that empowers them to make a well-informed choice in the free market. Such an initiative will also incentivize practices to remain competitive by either lowering their costs or by increasing the quality service provided to justify their high costs. It would be naïve to not acknowledge the obvious drawbacks of a system that exposes variation: it encourages practitioners to focus on volume rather than quality and may also encourage practices that currently charge a lower amount for their services to charge more.

To address these issues, it is important that there is a patient-centric definition of price transparency, one in which a patient has easy, real-time access to estimated out-of-pocket costs associated with any treatment or test recommended to them at any stage of the healthcare experience. An independent review of fees charged by specialists can be conducted by the Australian Competition and Consumer Commission (ACCC), the Productivity Commission, or another appropriately designated body. This review should not only analyse the fee structures themselves but also explore a range of policy steps that could be implemented to enhance fee transparency or to directly reduce the costs charged to patients.

In conclusion, this submission underscores an urgent call to rectify the grave issue of unregulated specialist fees and lack of transparency in pricing, which hits hardest those least able to bear it. Immediate legislative action in the form of policies like the ones suggested above are required to dismantle and repair a system that has failed its most vulnerable—the disabled. The current situation, where healthcare affordability is a privilege rather than a right, is unacceptable. It is time for decisive, clear-cut reforms that ensure equitable access to healthcare for all Australians, without exception.

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