

Mental health productivity commission (transcript of video):

Hello, my name is Amy and I am the mother and carer of a 12 year old boy who has autism and anxiety. He suffers greatly due to the lack of understanding and stigma in the broader community.

However, HE has access to the NDIS and funding for therapies to assist with his mental health and other challenges. And yes, there is a LONG way to go before the NDIS is fully functioning, but my son is in a far better place than so many others.

I recently attended the Ballarat community consultation, and one of the things that was extremely clear to me was that conversation was dominated primarily by those living with severe mental health issues such as schizophrenia or multiple personality disorder. It struck me as odd that no-one was talking about the enormous numbers of people experiencing medium to low level mental health problems every day due to their life circumstances - people such as the elderly or disability carers.

TODAY I wanted to talk about the thousands of unpaid, primary carers of people with disabilities. Most of us did not CHOOSE to be carers, and many of us will be carers for the rest of our lives.

We care because we love the people who need us, but caring takes a massive toll on OUR MENTAL HEALTH!

We give up plans, dreams, relationships, careers and much, much more - to give THEM the best life possible.

WE become ISOLATED from our friends, relatives and co-workers because OUR lives are 'different' and no longer 'fit in' to mainstream, 'normal' society.

I am one such carer. I care for my son who I love dearly but I spend my days 'on edge'.

When we are at home...

- I am listening to his repetitive questioning and emotional outbursts. He gets 'stuck' and needs someone to 'hear him' – even if it is hearing about the same problem over and over again.
- I feel like *I* am punished for the people who told him off for 'poor behaviour' throughout the day.

- At home, I feel trapped, doing the same activities, same routines day after day after day.

BUT if we go out...

- I am always watching, thinking and planning – where can we go that is safe? What if we see a dog? How can I keep his ‘volume’ at a reasonable level? Etc etc
- I am always trying to protect him from others - What will we do if people stare? What will I say if they tell him off or tell me I’m a bad mum?
- I feel sad watching all of the ‘normal’ families taking the ‘basics’ for granted – the parties, the footie matches, school fairs and going on holidays!

When he is at school

- I spend my days planning and organising and dealing with the ‘fires’. I make phone calls and pay bills and push all day to get him the services and therapies he needs.
- I think and reflect on what else I can do... because I NEED to do something else other than caring... but every resume I send, every application filled out is always sent in vain... Because who is going to hire me? I might have a PhD in sociology and a BA with honours... but my work history is patchy and I’ll mostly need to work from home...

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Carers like me end up sacrificing THEIR social, physical and MENTAL health in order to provide the best possible care for their loved ones. The rate of depression and anxiety among carers is alarmingly high, and this just isn’t good enough in 21st century Victoria!!

Yes, the federal government HAS invested some funds into the ‘Carer Gateway’ including extra money for counselling, coaching, peer support and so forth.

However, unpaid, primary carers DESERVE SOOO much more, and they NEED governments to invest extensively in improving unpaid, carers’ mental health for the LONG term!

Carers DESERVE to have a PURPOSE and a LIFE that does not just revolve around an unpaid caring role.

We DESERVE the opportunity to pursue OUR own dreams and goals.

We DESERVE to have more CHOICE and CONTROL over the direction of our lives.

To do this – Carers NEED TIME away from the unpaid, caring role to focus on ourselves and improve our mental, physical and social health.

We NEED governments to recognise that unpaid caring should NEVER be a one or two person job (if the goal is to avoid mental health problems). It will ALWAYS take a ‘village’.

We NEED governments to invest funding into RESPITE - giving unpaid carers access to meaningful, regular, lengthy breaks to pursue their dreams, take a holiday and participate in the everyday ‘normal’ activities they miss out on as unpaid, primary carers. Currently, ‘respite’ funding is primarily available based on the needs of the person with a disability, not the unpaid carer. For example, my son was allocated funds in his NDIS plan based on HIS need for after school ‘social activities’, not on MY needs for a holiday or break from the caring role.

We NEED governments to provide disability care REBATES (perhaps similar to child care subsidy) to allow unpaid, primary carers to re-enter the paid workforce, study or volunteer (should they wish to do so). This will have a major impact on carers’ mental wellbeing as it has the potential to improve their financial circumstances and increase their social/ intellectual activity. Currently the child care subsidy is only available for families of children under 12 years, and these mainstream services rarely provide care for teens/ adults with disabilities. In order to access disability care services, we have to apply for funds through our care recipients plan and the level of funding will be based on their need for social activity, not OUR desire to enter the paid workforce.

We NEED governments to provide tax incentives that encourage organisations to hire carers for PAID roles. We will likely experience patchy work histories, as we juggle the needs of our loved one with work and other family needs, and as such experience problems gaining meaningful paid employment. However, I would argue that being a carer gives us many transferrable skills that would be extremely beneficial to a whole range of organisations – if they would just give us a chance, AND we had access to appropriate alternative care arrangements for our loved one.