

Dear Commissioners,

**Response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of
People with Disability Issues Paper on Employment**

Please find below our response to the Issues paper regarding employment as published by the Royal Commission. This response is submitted on the basis that our Support Services Team engages in many conversations with our community members regarding this issue but does not necessarily reflect the individual views and experiences of any one community member.

Over 10,000 Australians live with Neurofibromatosis (NF). NF is a genetic condition of which there are three distinct types – NF1, NF2 and Schwannomatosis. Each variant causes (mostly) benign tumour to grow on nerves throughout the body. The impacts these tumours have on a person's life vary widely and are dependent on which body system is affected. For example, tumours behind the eye can result in visual impacts, whereas people with NF2 have tumours on their hearing nerves and invariably lose their hearing. Other common complications experienced by people with NF include physical disabilities (scoliosis, bone dysplasia), cognitive disabilities (specific learning disorders and/or auditory processing disorders), pain, itch and changes in sensation or motor skills. Small or large cutaneous tumours can cause significant cosmetic disfigurement.

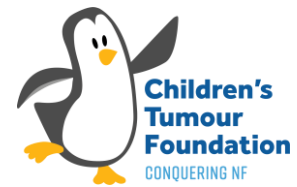
As the only national charity and peak body for Australians living with all three forms of Neurofibromatosis (NF), The Children's Tumour Foundation of Australia's (CTF) vision is to ensure tumours should never be a person's normal, and thus ensuring all Australians have the opportunity to live happy, healthy and fulfilling lives.

Medical interventions for NF are extremely limited, with surgery often being the only available approach to tumour removal. However, many tumours cannot be removed due to their location or the inherent risks their removal would have on function and therefore daily life. This means that many people impacted by these tumours experience long-term disability, thus making them vulnerable to the potential for abuse, violence, neglect, and exploitation throughout their lives. Employment for these individuals is often tenuous and challenging.

The CTF believe it is important that the experiences and needs of the community we support are taken into consideration by the Royal Commission when discussing matters regarding disability and employment for this group of individuals.

The severity of the symptoms experienced vary dramatically between people as well, which makes it even more challenging to define the overall experience of those living with NF in the disability space.

The way each of these three conditions impacts a person is different, but collectively they can cause a range of disabling symptoms not limited to: cognitive impairment, physical



disfigurement due to the presence of tumours or scoliosis, vision impairment, hearing loss, mobility issues, paralysis and chronic pain.

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The CTF detailed response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's issues paper on Employment

The issues paper covers a multitude of issues that members of the NF community indicate they have faced during their working years.

Due to the complexity of these conditions and the variable way they present, it is difficult to provide a one-size-fits all answer to the questions posed in the issues paper. Therefore, we have elected to outline some of the challenges members of our community face and the impacts this can, and has had, on their employment prospects and work-lives.

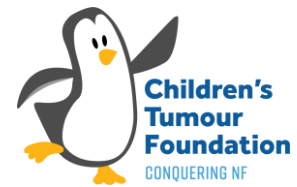
Life stages impact upon employment

People living with NF are often subjected to ongoing monitoring and surveillance, appointments, and treatments. In many instances a need for surgery and extended hospital stays or recovery periods often go hand in hand with their condition. Consequently, children miss out on significant amounts of their schooling and often fall behind their peers, both academically and socially. Many (up to 80% of children) experience mild cognitive impairment or specific learning disabilities and Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD). Many have issues with fatigue, concentration, and organisation. These issues significantly impact upon a child's ability to learn and thrive within the education system and in turn impacts their subsequent career prospects and ability to hold down employment.

The opportunities available to those impacted by NF are often further compromised by their educator's limited understanding of the condition and the impacts on learning. Often these children slip through the cracks in the education system as they are often labelled as naughty or disinterested. In reality, many simply cannot understand and need support, scaffolds and repetition to cope within an educational setting.

These challenges continue into adulthood and transfer from the classroom to the workplace. Without having been provided the tools to address these issues during childhood, adults are left without the skills to manage competing tasks which can adversely affect their employability and earning capabilities.

This lack of opportunity and the associated stigma and prejudice that is often experienced by individuals with NF means our community members frequently report episodes of bullying, isolation, neglect and loneliness. This can lead to ongoing mental health and confidence issues, which directly impact on their ability to seek and retain employment.



Community members report being ostracised and bullied at school due to their café-au-lait marks (large coffee coloured marks on the skin) and neurofibromas on the skin (small benign tumours) causing them to look different to their peers and their learning difficulties often resulting in them as being labelled “stupid” or worse.

Challenges with transition to and between employment

The CTF are aware that often the challenges these varying disabilities pose are not acknowledged by employers and work colleagues. Like their schooling years, adults with NF can be misconstrued as being awkward, having poor social skills or laziness. For example, an individual may have an impairment in executive functioning or working memory skills, and therefore require intensive or protracted training. If this is not recognised by their employer, there is the potential for abuse or exploitation due to an erroneous belief that there is a lower level of intelligence. Many people with NF do not reach their potential and are under employed in a direct attempt to counter this type of situation.

Due to these challenges and the difficulty in transitioning from school, many individuals often avoid tertiary education as they feel that the support offered will be less than in secondary or primary school. Many also feel that seeking and obtaining work is insurmountable, especially when coupled with physical difference through visible tumours on the skin, scoliosis, vision and hearing impairment.

Unfortunately for some people, employers have mistakenly assumed that tumours were contagious and have therefore excluded the person impacted with NF, even though they may have been well-suited and qualified for the position.

The CTF have also heard about potential employers often being unsure about how to access supports for their employees, which may influence their final decision in recruitment. They are therefore unwilling to take on someone with a disability due to the erroneous impression that they will be required to fund expensive modifications or additional training.

Others have indicated that employers do not know how best to support them in the workplace. If the individual with NF is young or newly graduated, this situation can be compounded by their inability to advocate for themselves. They also may be unsure of the exact supports or technology they require to satisfactorily complete tasks.

Again, these struggles arise when transitioning between jobs as the process begins again. This may be more challenging if the person with NF was not provided with suitable supports in their employment and have therefore been asked to leave after only a short period of time.

Accessing Job Supports

The information the CTF has received with regards to accessing job supports is mixed. While some people have felt well supported with Job Access and been allowed ready access to support equipment, often, we hear about the challenges people have faced in securing suitable aids for employment.

A lack of understanding on the part of the employer, assessor or disability employment advisor can mean that the full extent of the disability or challenges people with NF face is not recognised. Therefore, the supports required for these people to reach their full potential are not provided. As stated earlier, people with NF often find it difficult to advocate for themselves when they are suffering emotionally, they may not fully understand the implications of their condition.

Many people with NF experience invisible disability where they have frequent and chronic headaches or migraines; chronic pain caused by tumours compressing on nerves and the impacts of scoliosis on the spine. These inward conditions are often not recognised as sufficient to warrant access to support in employment despite the debilitating nature of these symptoms. This results in limitations, for example, an inability to stand for long periods, which makes job searching and retaining a job more difficult for those with NF impacted in these ways.

Anecdotally, when access to Disability Employment Services (DES) are available, the level of care and service provided been is extremely variable between providers. Some have reported positive experiences with Centrelink, in terms of assisting with interview skills and links to jobs and training; however, many NF community members indicate the level of support they are provided by local DES provider is minimal. They are often left with a promise of support, training opportunities and interview support, but few follow through.

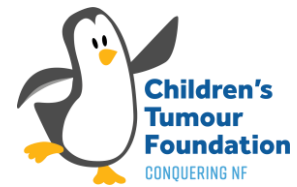
The learning difficulties experienced by people with NF1, means that advocating for themselves in this space can be daunting and anxiety-provoking thus compounding the process.

A significant number of people impacted by NF experience anxiety and depression with suicide rates being 100 times greater than the (early adult) general population. This contributes to the hesitation in reaching out for help to find work and to engage in employment. Support is greatly needed to assist with mental health in this space as well.

Harassment, Bullying, Exploitation and Neglect

Harassment and bullying are often reported to our Support Services Team. Stories about being regularly referred to as a “pimply-faced person” and the use of other derogatory and offensive terms are common. Many feel the need to suggest unproved methods of tumour removal, such as “using banana peel” or turmeric (unproven). These comments can and have come from both colleagues and employers.

Due to the complexity and variability of these conditions, many affected individuals are very insightful of their own limitations. This in turn leads to exploitation in the workplace, as they often overcompensate for perceived limitations. In combination with an inability to attain promotion or be recognised for the good work ensures that people with NF often feel like they are neglected in their workplace and have limited opportunities to progress their careers as others around them are able to do.



If an individual is required to have frequent periods of leave to attend hospital appointments or to recover from surgeries, they may feel inadequate and not part of a team.

The NF community are proud but modest, and often do not publicly reveal instances of exploitation and neglect. They often report an overpowering emotional impact that harassment and bullying due to appearance or other sensory impairments has on them and their ability to work. It is our privilege as an organisation that supports this community to recognise and understand that this is a common, but less recognised problem.

Concluding remarks

Thank you for the opportunity to provide feedback regarding employment for people with disability. People with Neurofibromatosis in all its forms, often fall between the cracks in educational and employment settings. These individuals should be considered as having disability in many instances and therefore their voices should be considered when considering the experiences of people with disability in employment.

We have focused here on the physical appearance and learning difficulties associated with NF; however, due to the progressive neurological nature of these conditions, physical disability and sensory impairment are also commonly experienced by individuals over the course of their lifetime. We have not covered these issues in detail within this submission as we anticipate that these impairments will be well covered by advocacy groups and peak bodies representing these disabilities.

Please contact us should you require further information regarding the contents of this submission.

Yours sincerely,

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Support Coordinator