JFA
Purple Orange

Submission to Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability about Rights and Attitudes

September 2020

About the Submitter

JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production and includes hosting a number of user-led initiatives.

Much of our work involves connecting people living with disability to good information and to each other. We also work extensively in multi-stakeholder consultation and collaboration, especially around policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community.

Our work is informed by a model called *Citizenhood*.

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Acknowledgments

JFA Purple Orange would like to thank the 97 people who responded to our recent survey about rights and attitudes. Their input was extremely valuable and has been incorporated throughout this submission.

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1. Summary and recommendations

Despite improvements in recent years, negative attitudes towards people living with disability persist. Many non-disabled Australians have limited understanding of inclusion and do not frequently interact with people who live with disability. Negative attitudes and a lack of understanding of the rights of people living with disability often go to the core of their mistreatment. Further, exclusionary practices – such as segregated schooling, housing, employment and social programs – are common and widely accepted as the norm. Some of these practices amount to violence, abuse, neglect and/or exploitation in and of themselves, while others increase the risk of such abuses occurring.

> **“A disability should not be a barrier.**
> **Being a woman should not be a barrier.**
> **Being old should not be a barrier.**
> **Being young should not be a barrier.**
> **What colour your skin is should not be a barrier.**
> **What you do, where you live, should not be a barrier.**
>
> **The barriers are human made.**
> **They are never a given with your human condition. We just make them up. We are now at the stage of life where we are challenging those made up assumptions. Let’s unmake them.**
> **At the end of the day it is all about our humanity.”**
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> ***Rachele, a woman living with disability***
> ***‘A Moment of Me’, JFA Purple Orange, July 2020***

There is a need to change the mindset of Australians towards disability. The barriers faced by people living with disability are not the result of physical, intellectual or psychological impairments, but stem from the way society is structured and functions. Diversity needs to be promoted and accepted as the norm from an early age, particularly in the education system, so that the next generation will naturally adopt a more inclusive approach. Proactive steps must also be taken to introduce more accessible and inclusive practices and approaches throughout work and community life. A stronger advocacy system is also needed to provide vital support to individuals and their families, strengthen the overall response system and serve as a deterrent against future incidents of violence, abuse, neglect and exploitation.

This submission makes a number of recommendations to improve attitudes towards people living with disability, increase understanding of (and respect for) their rights, and provide more comprehensive, accessible advocacy support in the case of rights violations. Our recommendations are as follows:

Recommendation 1

All educational institutions (including schools and tertiary institutions) to provide their staff, students, and students' families with information, resources, and education about diversity, inclusion, disability and human rights.

Recommendation 2

Commonwealth and state/territory governments to fund training in mainstream workplaces about diversity, inclusion, disability and human rights.

Recommendation 3

Commonwealth and state/territory governments to fund training on diversity, inclusion, disability and human rights in community settings, such as community centres, arts venues and sporting clubs.

Recommendation 4

State/territory governments to fund training for police on diversity, inclusion, disability and human rights, with a particular focus on communication with people who live with disability. This should be included as part of their formal training.

Recommendation 5

State/territory governments to fund training for mainstream health practitioners on diversity, inclusion, disability and human rights, with a particular focus on communication with people who live with disability. This should be included as part of their formal training.

Recommendation 6

Commonwealth and state/territory governments to provide greater funding for programs that educate people living with disability about their human rights.

Recommendation 7

Commonwealth and state/territory governments to provide greater funding for peer networks for people living with disability and family members to exchange their knowledge and experiences and learn about their human rights.

Recommendation 8

Mainstream media to better represent people living with disability and portray them just as people, without focusing on their disability.

Recommendation 9

Commonwealth and state/territory governments to allocate greater funding for large-scale positive messaging campaigns that normalise disability and highlight the contributions made by people living with disability.

Recommendation 10

Commonwealth and state/territory governments to establish inclusive education as the standard for all education settings (including schools and tertiary institutions).

Recommendation 11

All funding and programs to support people living with disability to gain employment to focus on securing mainstream waged employment.

Recommendation 12

All Commonwealth and state/territory government departments to lead the way in advancing disability employment outcomes by implementing strategies and actions to increase the number of people living with disability employed in their workplaces.

Recommendation 13

Commonwealth and state/territory governments to fund programs that ensure successful transitions for children and young people living with disability to primary school, secondary school, and life after school (including tertiary education and employment).

Recommendation 14

Commonwealth and state/territory governments to provide greater funding for peer networks for people living with disability and family members to exchange experiences and approaches with respect to participation in mainstream schools, workplaces, service providers and social activities.

Recommendation 15

State/territory and Commonwealth governments to provide sufficient long-term funding for individual and systemic advocacy services to meet demand, including in regional areas.[1]

Recommendation 16

State/territory and Commonwealth governments to provide an increased level of long-term funding for self-advocacy, peer advocacy, peer support networks and parent advocacy.

Recommendation 17

State/territory governments to each fund an ongoing disability advocate position, to identify and address systemic issues affecting people living with disability.

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[1] See also South Australia’s First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.10.

Recommendation 18

Advocacy providers to promote their services in the general public so that people living with disability, family members and the wider community are aware of available support.

Recommendation 19

Advocacy providers to promote general and context-specific (e.g. NDIS or DRC) advocacy services in the disability community, including through the NDIS and local area coordinators.

Recommendation 20

Advocacy services to employ more people living with disability as advocates and include people living with disability in decision-making about their service provision.

Recommendation 21

The Commonwealth Government to establish a central, national body to provide ongoing checks for advocates to ensure they are acting in their clients' interests.

Recommendation 22

Community visitors' schemes throughout Australia to be re-designed through consultation with people living with disability. This would include extending their mandate with respect to visitable places (to include private dwellings) as well as unplanned checks and audits.

2. Introduction

JFA Purple Orange has worked to enhance the life chances of people living with disability for over a decade. We strive to represent the voice of people living with disability in all our work and have extensive experience with co-design, consultation, focus groups, individual interviews, media work and support for peer networks. We ran a survey in July 2020 to inform this submission, with 97 responses. We also led a state-wide consultation in 2019 on behalf of the state government to inform the development of South Australia's first State Disability Inclusion Plan. Almost 400 people took part. We have drawn on the findings of this consultation and our 2020 survey throughout this submission, in addition to our regular and ongoing engagement with people living with disability.

3. Rights and attitudes

This section explains the prevalence and context of negative attitudes towards people living with disability, before considering the extent to which their rights are understood.

3.1. Prevalence of negative attitudes

One of the most common issues raised with JFA Purple Orange by people living with disability is the prevalence of negative attitudes towards, and a corresponding lack of understanding and appreciation of, people living with disability.

In the 2019 State Plan consultation, we asked respondents how inclusive they think the community is. Sixty-one per cent said not very or not at all. [2] Further, community attitudes was listed as participants' most significant disability-related frustration, alongside the built environment. [3] Participants spoke of negative attitudes, discrimination, a lack of understanding of disability and low recognition of the value of people living with disability. [4]

In a recent survey conducted in June 2020, we asked respondents to choose whether they would describe the attitudes of non-disabled Australians towards Australians living with disability as very positive, positive, neutral, negative or very negative. Of the 65 people who

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[2] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.4.

[3] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.5.

[4] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.6.

answered this question, fifty-one per cent said negative or very negative, 32 per cent said neutral and 16 per cent said positive. No one said very positive.

Despite this negative feedback, people living with disability have reported that disability is becoming more accepted over time and attitudes are slowly improving. [5] For example, in our recent survey, 58 per cent of respondents stated that the attitudes of non-disabled Australians towards people living with disability are a bit better or much better than five years ago.

3.2. The context of negative attitudes

Negative attitudes pervade everyday life for many people living with disability. When asked about the context in which they encounter such attitudes, respondents to our 2020 survey emphasised that they are everywhere, all the time. They explained that a non-inclusive mindset is engrained in our culture and way of life from early childhood, through schooling, and continuing into employment.

Respondents explained that negative attitudes are commonly displayed by strangers in public, such as in shopping centres, on public transport or at events. Young people are often the least respectful. Many respondents commented on the prevalence of negative attitudes in employment settings, as well as educational institutions. They also noted that some service providers, particularly in the health sector, fail to understand people living with disability and treat them poorly.

Similar findings were made during the 2019 State Plan consultation. One of the main barriers to employment identified during the consultation was the attitudes and practices of

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[5] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.5.

employers.[6] Similarly, the culture of education providers, stemming from their lack of disability understanding, was reported as resulting in inadequate levels of support for students and the persistence of exclusionary practices.[7] Negative attitudes were also reported on the part of some service providers.[8] This can result not only in insufficient protection against violence, abuse, neglect and exploitation, but also the occurrence of such practices at the hands of service providers themselves.

3.3. Knowledge of rights

People living with disability consistently tell JFA Purple Orange that they want to know more about their rights. For example, this was a key message to emerge from the State Plan consultation in 2019. Respondents felt that there is limited information about the rights of people living with disability, noting that it should not be assumed that all people have the resources, skills and ability to search for such information online.[12]

Our recent survey asked about people's knowledge of the rights of people living with disability. Of the 24 people living with disability who answered this question, 42 per cent said they know a little about their rights and 58 per cent said they know a lot. No one said that they do not know anything about their rights. It is worth noting that the people completing our survey are connected to our organisation and its information channels, and are therefore likely to be more informed and have more access to resources than others.

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[6] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.7.

[7] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.6.

[8] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.6.

When asked how they learnt about their rights, respondents living with disability explained that they primarily learnt through their lived experience and networks – some formal, such as peer groups, and others less formal, such as family and friends. Some learnt through work or study, while others learnt through media, including social media. A quarter of respondents living with disability had conducted their own research to learn about their rights, some driven by their own mistreatment.

Our recent survey also asked non-disabled people about their knowledge of the rights of people living with disability. Of the 62 people who responded, two said they don't know anything, 27 said they know a little and 33 said they know a lot. These respondents predominantly learnt about rights through personal experience (family member or friend) and their work (many work in disability or a related sector). Some respondents learnt about rights through their networks, such as volunteer groups, industry groups, the church, a community shed and peer support groups. Others were informed by disability rights activists and advocates. Several respondents had disability-related qualifications, while others have educated themselves or learnt through the media.

4. Violence, abuse, neglect and exploitation

This section explores how negative attitudes towards people living with disability and a lack of respect for their human rights can contribute to violence, abuse, neglect and exploitation. It describes the damaging impact that limited opportunities, low representation in decision-making and segregation from mainstream community life can have on people living with disability, before considering why some people commit violence, abuse, neglect and exploitation against them. Finally, this section considers how negative attitudes and lack of respect for human rights can adversely affect how the authorities and community members respond to violence, abuse, neglect and exploitation against people living with disability.

4.1. How attitudes and lack of respect for rights contribute to violence, abuse, neglect and exploitation

4.1.1. Lack of opportunity and representation in decision-making

Negative attitudes towards people living with disability, and a lack of acknowledgement of their rights, can result in less opportunities and lower representation in decision-making roles. This creates a breeding ground for exploitation and abuse. For example, if people living with disability do not receive the same education opportunities, they will have less employment prospects and are likely to end up working in disability employment enterprises, working in unskilled, low-paid jobs, or being unemployed. They may be perceived as not contributing to the community, or not having the capacity to contribute, placing them on the margins. They are also likely to end up in a lower socio-economic position than their non-disabled peers.

Combined, these factors render people living with disability as more vulnerable to violence, abuse, neglect and exploitation. Less educational opportunities could result in a lack of knowledge about their rights. Limited employment prospects may result in less resources to engage the support they need, particularly if their rights are violated. If they are not in the position to be contributing members of their communities, they are likely to be perceived as targets by those looking to exert their power over those who are vulnerable. They are also likely to have less informal social networks, which provide a vital safeguard in protecting people against violence, abuse, neglect and exploitation.

If people living with disability are on the margins, have a lower socio-economic status and are not well-represented in mainstream employment and community life, this is also likely to reduce the extent to which they are included in decision-making positions. This can result in laws, policies and programs that do not adequately protect people living with disability and promote their rights.

4.1.2. Segregation of people living with disability

Negative assumptions as to the skills and capacity of people living with disability sometimes results in their exclusion from mainstream opportunities and services. Examples include segregated schools or classrooms, disability-specific employment enterprises, and social programs exclusively for people living with disability. This can amount to violence, abuse, neglect and/or exploitation in itself and can also give rise to further incidents. Any concentration of vulnerable people, including those living with disability, increases the risk of exposure to violence, abuse, neglect and exploitation.

4.1.3. The reasons for mistreatment

To better understand the link between negative attitudes and violence, abuse, neglect and exploitation, we asked our 2020 survey respondents *why* they think non-disabled people sometimes hurt people living with disability or treat them badly.

The most common response overall[9] was ignorance or a lack of understanding, stemming primarily from a lack of education or personal experience with people who live with disability. Respondents explained that non-disabled Australians may not understand what it is like to live with disability and which words and actions can be offensive (such as jokes). Respondents who live with disability also noted a lack of compassion and empathy among non-disabled people.

The most common explanation given by respondents living with disability was that non-disabled Australians perceive them as vulnerable, easy targets and believe they will get away with mistreatment. They explained that potential perpetrators are aware that people living with disability are unlikely to speak up and/or fight back, particularly given that discrimination is accepted in our society and there are no (in their opinion) real consequences for mistreatment.

Respondents also explained that some non-disabled Australians perceive people living with disability as having little or no value – they are considered ‘sub-human’, with a lower status than their non-disabled peers. In the words of one respondent who lives with disability, ‘Our

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[9] This includes respondents living with disability and non-disabled respondents.

culture sees people with a disability as “less”, as a burden, why would it matter to hurt someone who is less than you?’

Power and control were also listed as reasons for the mistreatment of people living with disability. They explained that some non-disabled people want to exert power over people who cannot defend themselves, for their own gratification or personal gain. Others commented that some people are just unempathetic, disrespectful or outright cruel.

Respondents also explained that frustration can lead to mistreatment. Some non-disabled people are frustrated by the inconvenience caused by people living with disability and/or the prioritisation of resources into the disability sector. Others are exhausted from caring for people who live with disability, which can lead to frustration, burnout and sometimes eventually mistreatment.

4.2. How attitudes and lack of respect for rights affect responses to violence, abuse, neglect and exploitation of people living with disability

Negative attitudes and a lack of respect for the human rights of people living with disability can adversely affect the extent to which the authorities and community members respond to incidents of violence, abuse, neglect and exploitation.

4.2.1. The authorities

People living with disability have told JFA Purple Orange that when they report incidents of violence, abuse, neglect and exploitation to the police, they are not always believed. In particular, people living with intellectual disability feel that the police take the ‘side’ of the non-disabled offender, as they are able to recount their experience more convincingly.

Uninformed, inaccurate assumptions made by the police can result in incidents of violence, abuse, neglect and exploitation not being investigated. These attitudes can also make people reluctant to report incidents in future.

4.2.2. The community

Most non-disabled Australians are likely unaware that some common practices – such as segregated education for people living with disability – can amount to violence, abuse, neglect and exploitation. They might think that grouping people living with disability together in homes, social settings, schools and/or places of employment keeps them safer and less vulnerable. They might not realise that dissuading someone from becoming part of mainstream society can lead to a life of exclusion and vulnerability to violence, abuse, neglect and exploitation.

5. How to improve attitudes and knowledge of/respect for rights

This section considers ways to improve attitudes towards people living with disability and strengthen awareness of their rights.

5.1. Education for the wider community

If non-disabled Australians are led to believe from a young age that people living with disability have less to contribute to the community, they will treat them as such and are unlikely to develop inclusive attitudes and behaviours. It is therefore essential to better educate the wider community about the rights of people living with disability and the impact of segregation. When non-disabled people are educated about ableism and disability discrimination, they will understand the benefits of inclusion for everyone and are more likely to become allies of people living with disability.

There are different ways of learning: in addition to expanding inclusive practices so that diversity becomes the norm in all mainstream settings, it is important to proactively teach people about diversity, inclusion, disability and human rights. This was one of the main recommendations made through our 2020 survey and the 2019 State Plan consultation. [10] This includes general training to community members as well as more targeted training for people in specialist roles.

Recommendation 1

All educational institutions (including schools and tertiary institutions) to provide their staff, students, and students' families with information, resources, and education about diversity, inclusion, disability and human rights.

Recommendation 2

Commonwealth and state/territory governments to fund training in mainstream workplaces about diversity, inclusion, disability and human rights.

Recommendation 3

Commonwealth and state/territory governments to fund training on diversity, inclusion, disability and human rights in community settings, such as community centres, arts venues and sporting clubs.

Recommendation 4

State/territory governments to fund training for police on diversity, inclusion, disability and human rights, with a particular focus on communication with people who live with disability. This should be included as part of their formal training.

Recommendation 5

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[10] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.6.

State/territory governments to fund training for mainstream health practitioners on diversity, inclusion, disability and human rights, with a particular focus on communication with people who live with disability. This should be included as part of their formal training.

5.2. Education for people living with disability

It is essential for people living with disability to have a sound understanding of their rights, as well as available avenues of support and redress if their rights are violated. Rights education is empowering – it increases people's self-confidence and belief in their inherent value as a human being. Further, people who do not understand their rights are less equipped to identify rights violations – they may be mistreated without realising that the action was wrong, or may be more inclined to accept mistreatment as the norm for people living with disability.

Recommendation 6

Commonwealth and state/territory governments to provide greater funding for programs that educate people living with disability about their human rights.

Recommendation 7

Commonwealth and state/territory governments to provide greater funding for peer networks for people living with disability and family members to exchange their knowledge and experiences and learn about their human rights.

See also recommendations regarding advocacy and self-advocacy below, particularly recommendations 16, 18 and 19.

5.3. Media

People living with disability often comment that they are not adequately represented in mainstream media, including television series and films. Similarly, people living with disability are seldom represented through social media, except by individuals and organisations that specifically work with, or represent the interests of, the disability community.[11]

People living with disability have long called for greater representation in television shows, advertising, films, and the media. This was echoed in our recent 2020 survey, with multiple calls for people living with disability to be represented just as people, without focusing on their disability. There were also strong calls for more positive messaging to normalise disability, reduce stigma, highlight people's successes, and emphasise the similarities all people share, irrespective of their ability. Participants in the 2019 State Plan consultation similarly called for a state-wide inclusion campaign and funding for positive messaging campaigns. [12]

Recommendation 8

Mainstream media to better represent people living with disability and portray them just as people, without focusing on their disability.

Recommendation 9

Commonwealth and state/territory governments to allocate greater funding for large-scale positive messaging campaigns that normalise disability and highlight the contributions made by people living with disability.

5.4. Social interaction

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[11] For example, see: South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.16.

[12] South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020).

A key source of many of the problems raised by people living with disability is a lack of understanding on the part of non-disabled Australians. This stems from the fact that many non-disabled Australians do not interact with people who live with disability at school, work or in their social lives. The root cause of this is the persistence of segregation and the lack of accessible and inclusive approaches in schools, workplaces, service provision and the community more generally. It is harder for non-disabled people to develop inclusive attitudes and behaviours if they do not interact with people living with disability from a young age.

Respondents to our 2020 survey emphasised the importance of non-disabled Australians spending time with people who live with disability. If people living with disability were genuinely included in all areas of mainstream society, resulting in more interaction with non-disabled Australians, this would likely have a major impact on the prevalence of negative attitudes as well as the incidence of violence, abuse, neglect and exploitation.

Achieving a more inclusive community would require changing the attitudes of non-disabled Australians and teaching people living with disability and their family members about the long-term benefits of inclusion. Some people living with disability and their family members are afraid that shifting from the comfort of segregated settings to the mainstream will make their lives worse. For example, some families of children living with disability have told JFA Purple Orange in the past that their children are ‘happy’ in segregated educational settings and fear mistreatment in mainstream classrooms/schools.

Recommendation 10

Commonwealth and state/territory governments to establish inclusive education as the standard for all education settings (including schools and tertiary institutions).

Recommendation 11

All funding and programs to support people living with disability to gain employment to focus on securing mainstream waged employment.

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All Commonwealth and state/territory government departments to lead the way in advancing disability employment outcomes by implementing strategies and actions to increase the number of people living with disability employed in their workplaces.

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Commonwealth and state/territory governments to fund programs that ensure successful transitions for children and young people living with disability to primary school, secondary school, and life after school (including tertiary education and employment).

Recommendation 14

Commonwealth and state/territory governments to provide greater funding for peer networks for people living with disability and family members to exchange experiences and approaches with respect to participation in mainstream schools, workplaces, service providers and social activities.

6. Advocacy

This section considers current gaps and issues with respect to individual advocacy, self-advocacy and systemic advocacy programs and services, then provides recommendations as to how these could be improved. It then explains how a stronger advocacy system could reduce the extent to which people living with disability experience violence, abuse, neglect and exploitation.

6.1. The current situation

6.1.1. Individual advocacy services

During the State Plan consultation in 2019, participants noted that advocacy services work well but are under-staffed and under-resourced, resulting in long waiting lists. Further, they explained that some people do not know where to seek advice and support. The need for advocacy was raised across a range of topics, including discrimination and rights protection, education, employment, health and housing. They raised a particular need for more advocacy services in regional areas.[13] Consultation participants suggested that greater understanding of rights and more funding for advocacy services would increase their safety.[14]

Nineteen respondents to our 2020 survey said they have used advocacy services, and all but one found this helpful. Advocacy services were used for a range of issues including an insurance claim, Royal Commission submissions, gaining employment, making a Discrimination Act complaint, resolving a housing issue, applying for the Disability Support Pension, telecommunications issues, assistance with legal proceedings, a stillbirth and sexual assault.

Advocacy services are providing valuable support to survivors of violence, abuse, neglect and exploitation. For example, in its 14 May 2020 newsletter, the Disability Advocacy Network of Australia reported on a survey conducted with advocacy organisations around Australia. Abuse/neglect/violence was the third most common issue raised by people living with disability, following government payments and NDIS Access/Planning.[15]

6.1.2. Self-advocacy

Self-advocacy groups provide vital support to people living with disability, strengthening their understanding of their rights and confidence to speak out. Self-advocacy groups like Our Voice SA, supported by JFA Purple Orange, are helping to build the confidence of people

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[13] South Australia’s First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.10.

[14] South Australia’s First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.11.

[15] https://us9.campaign-archive.com/?u=549c507664a643e2890c363a4&id=9eefab00b0#SnapshotSurvey.

living with intellectual disability to speak up about what is important to them. In this short video, two members of Our Voice SA talk about what self-advocacy means to them.

6.1.3. Systemic advocacy

Systemic advocacy organisations play an important role in raising awareness of issues facing people living with disability and advocating for change. Systemic advocacy can have the power to change not only laws, policies and programs, but also attitudes towards, and the treatment of, people living with disability. At present, funding arrangements result in inadequate resources for systemic advocacy.

6.2. How to improve advocacy services

6.2.1. Funding

When asked how advocacy services could be improved, the main recommendation from 2020 survey respondents was to provide more funding and more services. There was a strong message that there are not enough advocacy services in South Australia. There are long waiting times to receive services, which are then only available for a limited time. When a matter is urgent, people need an immediate response. Some commented that advocates are too busy assisting NDIS participants to deal with other matters. In addition to general advocacy services, funding was specifically called for to support peer advocacy, self-advocacy and parent advocacy.

Recommendation 15

State/territory and Commonwealth governments to provide sufficient long-term funding for individual and systemic advocacy services to meet demand, including in regional areas.[16]

Recommendation 16

State/territory and Commonwealth governments to provide an increased level of long-term funding for self-advocacy, peer advocacy, peer support networks and parent advocacy.[17]

Recommendation 17

State/territory governments to each fund an ongoing disability advocate position, to identify and address systemic issues affecting people living with disability.

6.2.2. Promotion of services

When asked how advocacy services could be improved, the second most common recommendation made by 2020 survey respondents was greater promotion of available services. They explained that some people living with disability do not know that advocacy services exist or are not comfortable accessing them. More information is needed not only about their existence, but precisely what they can offer. Some people living with disability are too intimidated or afraid to contact an advocate. Promotion of services therefore also needs to reassure potential clients and give some insight into what the process will entail.

The importance of the wider community being aware of advocacy services was also raised, as this could serve as a deterrent against violence, abuse, neglect and exploitation.

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[16] See also South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.10.

[17] Support for self-advocacy programs and peer support networks was also called for during the 2019 State Plan consultation. See South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/__data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.10.

The issue with promoting advocacy services more widely at present is that most are already at capacity, with long waiting lists. Better promotion of available advocacy services needs to be coupled with greater, long-term funding for services to expand throughout Australia.

Recommendation 18

Advocacy providers to promote their services in the general public so that people living with disability, family members and the wider community are aware of available support.

Recommendation 19

Advocacy providers to promote general and context-specific (e.g. NDIS or DRC) advocacy services in the disability community, including through the NDIS and local area coordinators.

6.2.3. Involvement of people living with disability

Several 2020 survey respondents commented that advocacy services should employ and/or seek input from more people living with disability.

Recommendation 20

Advocacy services to employ more people living with disability as advocates and include people living with disability in decision-making about their service provision.

6.2.4. Oversight of advocates

Respondents to our 2020 survey explained that a person's advocate might be the only voice they have. Advocates are reportedly sometimes bullied into silence or influenced by others. It is essential that advocates are independent and act in the interests of their clients.

Recommendation 21

The Commonwealth Government to establish a central, national body to provide ongoing checks for advocates to ensure they are acting in their clients' interests.

6.2.1. Community Visitor Schemes

There are currently six Community Visitor Schemes (CVS) for people with disability operating across Australia, one in each state and territory except Western Australia and Tasmania. Each scheme operates differently and separately from the others. A review of these schemes was conducted in 2018.

Since this review and the transition to the NDIS, the role of the CVS in South Australia has been limited to services either provided or funded by the State Government. This means that CVS visitors no longer have the legal authority to visit the homes of people with disability. They can only visit disability accommodation premises and day options program premises.

One of the SA visitors' roles is to act as advocates for residents and for persons attending day options programs to promote the proper resolution of issues relating to the care, treatment or control of such persons.[18] This provides a vital safeguard against violence, abuse, neglect and exploitation. It is essential that this important safeguard is extended beyond these limited settings.

Recommendation 22

Community visitors' schemes throughout Australia to be re-designed through consultation with people living with disability. This would include extending their mandate with respect to visitable places (to include private dwellings) as well as unplanned checks and audits.

6.2.2. Other

Respondents to our 2020 survey made a number of other suggestions as to how advocacy services could be improved, including:

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[18] *Disability Services (Community Visitor Scheme) Regulations 2013* (SA) 2017 s4(1)(c).

- Using person-centred approaches e.g. youth friendly approaches for young people;
- Providing specialised services for people with particular disabilities such as autism;
- Providing independent advocacy services to avoid any risk of bias or conflict of interest; and
- Providing a national, 24-hour free advocacy phone service for people living with disability.

6.3. Link between advocacy and violence, abuse, neglect and exploitation

To gain some insight into the link between advocacy and violence, abuse, neglect and exploitation, we asked 2020 survey respondents whether they think such abuses would reduce in frequency if people living with disability could access free advocacy support whenever they needed it. Seventy-six percent said yes, 5 per cent said no and 19 per cent said they did not know.

We asked respondents to explain how access to free advocacy support could reduce how often people living with disability experience violence, abuse, neglect and exploitation. Providing access to free advocacy support is clearly not a silver bullet for the prevention of harm, but respondents' answers made it clear that it would help to reduce its incidence.

The main explanation given was that access to free advocacy support would empower people living with disability by teaching them to speak up for themselves, giving them confidence and knowledge, explaining their rights and options and providing essential support. One respondent explained that people living with disability are at their most vulnerable when they feel alone. If they felt they had someone to contact, answer questions, provide information and offer emotional and practical support, they would feel stronger and less vulnerable. They would also be more likely to take action and expose wrongdoings, which could serve as a deterrent for potential perpetrators in future. In the words of one respondent, the person living with disability would be “well-supported to make choices that promote change.”[19]

Another explanation given as to why free advocacy support would reduce the frequency of abuses was that this would increase accountability and serve as a deterrent for potential future perpetrators. As one respondent explained, this would “make it clear to abusers that someone with power to intervene is watching.”

Respondents commented that access to free advocacy services would also remove a major barrier for some people living with disability: cost.

> **“[A]ny safeguarding system in the disability environment cannot operate optimally in the absence of a robust, dynamic and well-resourced advocacy system…”**
>
> ***Commonwealth Ombudsman’s submission to the 2017 review of the National Disability Advocacy Program***

Finally, respondents noted that if quality, free advocacy services were available to people living with disability, it is likely that levels of reporting incidents of violence, abuse, neglect and exploitation would increase. This, in turn, could deter potential perpetrators and influence governments to take more steps to prevent and respond to such abuses.

7. Rights, attitudes and Aboriginal and Torres Strait Islander peoples

We cannot claim specific insights into the situation of Aboriginal and Torres Strait Islander peoples (ATSI) in this submission, but would like to draw the DRC’s attention to two recent

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[19] Respondent to July 2020 survey on rights and attitudes.

studies. We hope these will provide useful information about the attitudes of ATSI peoples towards autism:

- R Lilley, M. Sedgwick and E. Pellicano, ‘Inclusion, acceptance, shame and isolation: Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia,’ *Autism* (2020).
- R Lilley, M. Sedgwick and E. Pellicano, ‘We look after our own mob: Aboriginal and Torres Strait Islander Experiences of Autism,’ *Macquarie University* (2019).

8. Conclusion

Thank you for the opportunity to provide input on this important topic of rights and attitudes. The issues discussed in this submission affect all areas of life for people living with disability, so it is vital that concrete action is taken to address them.

Please contact us if you would like to discuss any aspect of this submission in more depth.