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# Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability about Group Homes

14 August 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 people living with disability and their family members for sharing their experiences in relation to group homes with us.

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### Contents

1.	Sur	mmary and recommendations4
2.	Int	roduction7
3,	Qu	estion 2: What is your opinion of the quality of life for people with disability in a
gro	oup h	ome?7
3	3.1.	The meaning of home (home vs house vs facility)7
	3.2.	Why group homes exist in Australia9
	3.3.	Imagining a good life11
	3.4.	Proposed changes to SIL12
	3.5.	Group homes as a form of violence, abuse, neglect and exploitation
4.	Qu	estion 6: Is there a continuing role for group homes in providing accommodation for
pe	ople	with disability? If so, what is the role? If not, what are the alternatives?16
	4.1.	The role of informal supports
	4.2.	Investment in Social Capital19
5.	Qu	estion 7: Are you aware of the use of restrictive practices in group homes?21
6.	Cor	nclusion24
7.	Ref	ferences

### 1. Summary and recommendations

In this submission JFA Purple Orange addresses the following questions from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Issues Paper on Group Homes:

## Question 2: What is your opinion of the quality of life for people with disability in a group home?

In this section we delve into the meaning of home and examine the difference between a home, a house and a facility. We argue that group homes possess none of the characteristics of a home and that this has a negative impact on the quality of life of people living with disability. We explain how so many people living with disability have experienced living in a group home by looking at previous funding mechanisms. The Model of Citizenhood Support is used to describe how investment in the Personal Capital of a group home occupant can assist them to imagine a good life for themselves outside of an institutional setting. Finally, we posit that group homes represent a form of violence, abuse, neglect and exploitation of people living with disability.

### Question 6: Is there a continuing role for group homes in providing accommodation for people with disability? If so, what is the role? If not, what are the alternatives?

JFA Purple Orange believes there is not a continuing role for group homes in their current form in providing accommodation for people living with disability. In this section we look at how proper investment in planning and better education about and uptake of individualised living options can result in better outcomes for people living with disability. We also discuss the important role of informal supports and investment in Social Capital can help to keep people safe, using COVID-19 and the untimely death of Anne Marie Smith to demonstrate how formal supports alone cannot (and do not) protect people from harm, whether they live alone or in a group home.

#### Question 7: Are you aware of the use of restrictive practices in group homes?

Our response to this question explains the different types of restrictive practices and uses examples of restrictive practices experienced in group homes by people living with disability as told to us by their family members. We also highlight the importance of informal supports safeguarding people living with disability from restrictive practices.

In this submission we recommend:

#### **Recommendation 1**

JFA Purple Orange believes the following recommendations of the Parliamentary Joint Committee on the National Disability Insurance Scheme in its Final Report on Support Independent Living should be implemented by the Federal Government as a matter of urgency:

- Recommendation 18: The committee recommends that the NDIA review its existing
  policies and procedures, to ensure that participants needing assistance with daily
  living are given genuine choice as to whether they access supports in a shared for
  individual living arrangement.
- Recommendation 19: The committee recommends that the NDIA give all participants living in congregate settings, who receive SIL funding, the opportunity to review their accommodation and support arrangements and to exit the congregate setting if they wish to do so.
- Recommendation 20: The committee recommends that the NDIA review and, if necessary, amend the SIL quoting tool, to ensure that it allows participants to choose the people with whom they share a residence to the greatest extent possible.
- **Recommendation 21:** The committee recommends that additional funding be made available to support participants seeking to exit congregate living arrangements
- Recommendation 24: The committee recommends that the NDIA implement a mechanism to separate service delivery, tenancy management and support coordination for participants in SIL settings
- **Recommendation 25:** The committee recommends that the NDIA, with the Quality and Safeguards Commission, implement a mechanism to ensure participants

5

accessing SIL are able to change providers without compromising housing security or suffering other adverse consequences.

### **Recommendation 2**

The role of informal supports in assisting a person to achieve their individual living preferences should be considered in the NDIS planning process.

#### **Recommendation 3**

Federal, State and Territory Governments should invest in projects that advance inclusive neighbourhoods and promote informal supports as a means of safeguarding people living with increased vulnerability.

#### **Recommendation 4**

As part of every Plan review, the NDIA should examine the Social Capital of Scheme participants to identify where increased reliance on formal supports may put them at risk of experiencing violence, abuse, neglect or exploitation. Measures should then be put in place to support the participant to make and strengthen connections in mainstream community life.

6

### 2. Introduction

The concept of home is integral to a person's sense of their own identify and is an important determinant of their quality of life. Home should give you a sense of belonging. It is where you should feel safe, where you are free to be yourself and where you have control over who comes and who goes. Currently, group homes in Australia do not provide residents with these things. They deprive residents of choice and control about how they live, where they live and often with whom they live. This is a perverse situation given many residents are in group homes as a result of funding through their NDIS packages (as recipients of either Support for Independent Living funds or Supported Disability Accommodation funds). As our submission will demonstrate, these arrangements lead to a lack of individualised funding and supports for residents and a lack of flexibility to facilitate their preferred living arrangements. In this submission we advocate for reforms to the way people are funded in relation to their accommodation options.

# 3. Question 2: What is your opinion of the quality of life for people with disability in a group home?

### 3.1. The meaning of home (home vs house vs facility)

Any discussion about the quality of life for people living with disability living in group homes must begin with an examination of the language we use to describe where people live, because the difference between a home, a house and a facility is immense.

The meaning of home has been previously discussed in consultations and workshops run by JFA Purple Orange with people living with disability and their families. Quotes from these forums reflect on the meaning of home, and how group home settings do not meet that meaning:

- "Home is not where you live but where they understand you"
- "For many people with a disability and other vulnerable people, home becomes a 'business' with rules, regulations, constant intrusion and lack of control"

7

ISS.001.00369\_01\_0008

- "Home is 'who we are', and thus is expected to stay true to our nature and identity.
   When home achieves this end, we are content and fulfilled. When it does not, we can experience discontent, distress and unhappiness"
- "We all need to resist the temptation to associate the strong walls of institutions with protection from harm. We need to resist the temptation of seeing the congregation of people with disability as anything like family life"
- "A facility can never replace home. The best that can be achieved are some vague features of something that is homelike"
- "Group homes are where people live together by circumstance, not choice"

JFA Purple Orange believes the difference between a home, a house and a facility can be described as follows:

A **home** is a place of safety, rest, renewal, love and belonging. It is where you are free to be yourself, where you are free to personalise your surroundings and where you can imagine a future for yourself. It is the gateway for your participation in community life and where you make decisions about who can enter your home and on what terms. Home is also means membership of the local street, the local neighbourhood, as a valued visible neighbour.

A **house** is a place to live but it lacks the emotional aspects of a home, like feelings of love and belonging. Your ability to control and enjoy your surroundings is limited by external factors such as rules imposed by landlords or the habits of other people you live with.

A **facility** is first a foremost a workplace with hallmarks typical of a place of employment such as break rooms for staff, paperwork on display and emergency evacuation procedures on the walls. The fact that people live in the facility is a secondary consideration. People who live in facilities have no control over who they live with, who else can enter the facility and when those other people are there. Based on the above descriptions, the term 'group home' is therefore a misnomer, as these places have none of the characteristics of a home and all the characteristics of a facility. This in turn has huge implications on the quality of life of persons living with disability.

### 3.2. Why group homes exist in Australia

Historically, many Australians living with disability were forced to live in institutions. Nowadays, most (but not all) larger residential institutions have closed. However, many people living with disability (particularly intellectual disability) continue to live in congregate housing arrangements such as group homes, cluster housing, supported residential facilities and aged care facilities. These residences are shared with unrelated people, sometimes with similar support needs but not always, and supervised by support staff. The NDIS reports that as of March 2020 there were 22,848 Scheme participants with SIL funding and 13,944 participants with SDA funding in their plans.<sup>1</sup>

While group homes do not tend to carry *all* of the problems of large residential institutions, they typically still retain several institutional characteristics:<sup>2</sup>

- Limited or no choice of whom to live with including size of household; to what
  extent people get on with the other people in the household; an option to live alone
  or with a partner, other relatives or friends who may or may not live with disability
- Limited choice of service provider and obligatory sharing of assistance with others in the household
- Once arrangements are in place, it can be difficult to change accommodation, housemates or service providers, even if they become unsatisfactory to a resident

<sup>&</sup>lt;sup>1</sup> National Disability Insurance Scheme, COAG Disability Reform Council, Quarterly Report, 31 March 2020, p 472.

 <sup>&</sup>lt;sup>2</sup> United Nations, Committee on the Rights of Persons with Disabilities General Comment No. 5 (2017) on living independently and being included in the community, pages 4-5, accessed on 13 May 2020 at <a href="https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx">https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx</a>

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- Feel more like facilities delivering services than like homes managed and run by service providers, with residents having limited control over what happens there and limited opportunity to make the space their own or to host visitors
- Have fairly rigid routines and require residents to do activities as a group
- Expose residents to increased likelihood of being subjected to regulated restrictive practices, especially environmental restraints that limit their access to or control over shared amenities such as fridges, particular rooms of the house, mealtimes, activities, etc.<sup>14 15</sup>
- Segregate rather than acting as a gateway to community inclusion because neighbours view them as service venues rather than regular homes
- Expose residents to vulnerability from abuse or exploitation from staff and other residents through segregation and 'behind-closed-doors' practices.

Even though the NDIS was intended to advance choice and control, and social and economic participation (neither of which group homes are known for delivering), group homes in Australia persist largely as a result of government funding in the form of Supported Independent Living (SIL). SIL is most commonly used as a mechanism for funding service providers to offer shared supports to NDIS participants in a shared living arrangement, and has enabled people living in group homes to be transitioned from government block-funded services to NDIS funded services without any change to their living arrangements. While the main motivation for this transition may have been ensuring people living with disability did not end up homeless, SIL has served to entrench a housing model that does not meet the needs or wants of people living with disability, and certainly impedes their ability to ever feel 'at home' where they live.

In SIL settings a whole house is assigned a Local Area Coordinator who invites the existing provider to quote for all occupants. This can lead to a service provider conflict of interest and the embedding of supports based on housing all occupants as a group, rather than the individual supports required by each occupant. This has a direct impact on the quality of life of each resident as their individual needs and aspirations are considered only in the context

of the needs and aspirations of the people they are living with; people, it should be noted, they likely did not choose or agree to living with in the first place.

As a result of this service provider conflict of interest, residents in a group home may all be required to eat their meals at the same time as more support workers are rostered on then, instead of when the residents choose to eat. This controlling behaviour by staff can escalate to the exercise of restrictive practices, such as locking fridges over night or dispensing medications to all residents at the same time, despite some medication needing to be carefully timed around food consumption. The use of restrictive practices in group homes is further discussed in section 5 of this submission.

JFA Purple Orange believe there should not be a separate SIL process in the NDIS. The individualised budget pathway should be the same for all NDIS participants, regardless of their current living arrangements. There also needs to be investment in planning assistance for current group home occupants, to help them work out for themselves what a good life looks like and what their preferred living arrangements are to facilitate that.

### 3.3. Imagining a good life

The Model of Citizenhood Support<sup>3</sup> can be used to support group home occupants imagine a life for themselves outside of such institutional settings. Citizenhood describes a situation where a person is an active and valued member of their local community. Their lifestyle is informed by personally defined choices and they are able to grow through their involvement in meaningful activities and by their participation in a network of relationships characterised by acceptance, belonging and love. Citizenhood comprises roles that are valued by our communities; family member, friend, neighbour, worker, customer, etc.

<sup>&</sup>lt;sup>3</sup> Williams, R. (2013), *Model of Citizenhood Support: 2nd edition*, Julia Farr Association Inc, Unley South Australia. **11** 

The Model of Citizenhood Support is a framework for determining what kind of assistance might be most helpful to a person in circumstances where there are perceived disadvantages such as physical or mental impairment or a lifestyle characterised by a relative poverty of resources and opportunities. By examining how a person can call upon their four key areas of Capital (Personal Capital, Knowledge Capital, Material Capital and Social Capital), it is possible to determine how a person's life chances will enable them to live a good life through exercising life choices. In the context of choosing living arrangements, there must be investment in the Personal Capital of group home occupants, including supporting their vision of a good life and providing them with authentic control over their decisions and actions. Group home providers must recognise they have a fundamental obligation to uphold occupants' Personal Capital. This means the provider must carry out its endeavours in ways that do not inadvertently (or intentionally) undermine a person's view of their own potential, their strengths, their personal vision of what might be possible in their life, and their personal leadership as a decider and actor. Recent proposed changes to SIL go some of the way to supporting group home occupants enjoying more vision and control over their living arrangements, however ongoing investment in their Personal Capital is required in order to genuinely advance their life chances.

### 3.4. Proposed changes to SIL

SIL.

The future financial viability of the NDIS is at risk due to the significant costs associated with

As a result the

Federal Government has been exploring ways to reform the SIL process.

The Parliamentary Joint Committee on the National Disability Insurance Scheme inquired into Supported Independent Living during 2019 with its final report released in May 2020. The committee made a number of significant observations, findings and recommendations in relation to SIL, particularly around the ability of this funding mechanism to thwart the choice and control or participants when it comes to where and with whom they live. However, the Federal Government is yet to release its response to the final report so the extent to which the Committee's recommendations will be implemented is currently unclear.

Recommendation 1: JFA Purple Orange believes the following recommendations of the Parliamentary Joint Committee on the National Disability Insurance Scheme in its Final Report on Support Independent Living should be implemented by the Federal Government as a matter of urgency:

- **Recommendation 18:** The committee recommends that the NDIA review its existing policies and procedures, to ensure that participants needing assistance with daily living are given genuine choice as to whether they access supports in a shared for individual living arrangement.
- **Recommendation 19:** The committee recommends that the NDIA give all participants living in congregate settings, who receive SIL funding, the opportunity to review their accommodation and support arrangements and to exit the congregate setting if they wish to do so.
- **Recommendation 20:** The committee recommends that the NDIA review and, if necessary, amend the SIL quoting tool, to ensure that it allows participants to choose the people with whom they share a residence to the greatest extent possible.<sup>5</sup>
- **Recommendation 21:** The committee recommends that additional funding be made available to support participants seeking to exit congregate living arrangements

<sup>&</sup>lt;sup>5</sup> In relation to Recommendation 20, JFA Purple Orange believes the Committee could have gone further by recommending that quotes prepared by a provider are given directly to the participant. 13

- Recommendation 24: The committee recommends that the NDIA implement a mechanism to separate service delivery, tenancy management and support coordination for participants in SIL settings
- Recommendation 25: The committee recommends that the NDIA, with the Quality and Safeguards Commission, implement a mechanism to ensure participants accessing SIL are able to change providers without compromising housing security or suffering other adverse consequences.

### 3.5. Group homes as a form of violence, abuse, neglect and exploitation

Experiencing violence, abuse, neglect or exploitation will undermine a person's quality of life, irrespective of whether they live with disability or not. However, as the Commission has seen from the written submissions and verbal testimonies it has received, people living with disability are more vulnerable to experiencing such behaviours. A person's journey into a group home, and their experiences once they are living in that setting, may have characteristics of violence, abuse, neglect and exploitation.

It's possible that residents of group homes who do not wish to be there could be said to have been exploited as a result of their disability. For example, they may not have been given the opportunity to speak up for themselves about their preferred living arrangements, or they may not have had a family member, friend or advocate to assist them with voicing their preferences and concerns. Even where the person living with disability has voiced their concerns, they (and their families) may have been told there are no other suitable housing or that a group home is the best option for them.

The 2009 SHUT OUT report on the experience of Australians living with disability and their families details why many people living with disability remain in group homes – it is often the only way people can access social and personal care supports, since such supports have typically been offered only to those residing in particular congregate settings:

"It is reasonable to argue that very few people living in group homes would choose to live in such a setting if they had a realistic choice. It is a compromise brought about

14

by necessity, as they do not have enough support through funding for paid support, even augmented by their family and informal support networks, to live in their own home..."<sup>6</sup>

Families of people living with disability are particularly vulnerable to being exploited, particularly where they live together as a family unit and one or more family members demonstrate behaviours of concern. Families in these situations have reported to JFA Purple Orange that they are exhausted, stressed and overwhelmed. As a result, if they are told a group home is the only realistic or available option for their family member living with disability, they may not be in an emotional or financial position to meaningfully challenge that assumption.

Residents in group homes (particularly those who are there by virtue of SIL funding) could be said to have had their right to find a home reflective of what they want neglected by virtue of transitional arrangements put in place to secure their housing. This neglect continues as SIL funding arrangements further entrenched their position in a group home and failed to assist them into a living arrangement of their choice.

Discussions in JFA Purple Orange consultations and workshops have raised the issue of safety, or rather the lack thereof, in group homes. Feeling under threat from other residents' violent or aggressive behaviour was a common concern, together with feeling vulnerable as a result of having little to no control over support workers and other visitors to the house. Theft of money and other personal belongings, intimidation by support workers and a lack of autonomy (choosing what to do and when) were other common experiences in group home settings.

<sup>&</sup>lt;sup>6</sup> SHUT OUT: The Experience of People with Disabilities and their Families in Australia, page 27, accessed on 12 May 2020 at <u>https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia 15</u>

The outbreak of COVID-19 has further highlighted just how vulnerable people living with disability in group homes are. In its Statement of Concern dated 26 March 2020, the Commission explained the potential consequences of group homes using 'lockdown' measures in an effort to reduce the risk of infection:

Such measures may also have the unintended consequence of reduction of formal oversight mechanisms (such as Community Visitor Schemes) and informal oversight provided by family, friends, supporters and advocates. With the decrease of oversight comes an increase in the risk of violence, abuse, neglect and exploitation.<sup>7</sup>

JFA Purple Orange is deeply concerned by the link between group homes and the violence, neglect, abuse and exploitation of people living with disability. As we explain in response to Question 6 below, we believe there is not a continuing role for group homes in Australia in their current form.

### 4. Question 6: Is there a continuing role for group homes in providing accommodation for people with disability? If so, what is the role? If not, what are the alternatives?

JFA Purple Orange believes group homes *as they currently exist* should not continue to play a role in providing accommodation for people living with disability. Settings where multiple people live together should only occur when two non-negotiable conditions are met: firstly, residents genuinely choose to live together (and it's an informed choice, authentically facilitated through methodologies such as Supported Decision Making); and secondly, their funding and support packages are based on their individual needs alone, not in the mutual context of the needs of the other residents.

<sup>&</sup>lt;sup>7</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2020. Statement of Concern - The response to the COVID-19 pandemic for people with disability. [ONLINE] Available at: <u>https://disability.royalcommission.gov.au/publications/statement-concern-response-covid-19-pandemicpeople-disability</u>. [Accessed 31 July 2020]. 16

In order for people living with disability to exercise genuine choice and control about their living arrangements, there must be investment in NDIS planning assistance so that Scheme participants are supported to make informed decisions about where and with whom they live. This kind of support is important throughout a person's life, however there are particular moments in time when it will be crucial, for example when someone is moving out of home for the first time or where they are a current resident in a group home. Integral to this planning assistance will be the availability of planners with a detailed understanding of alternatives to group homes and an attitude that all people living with disability can and should decide where and with whom they live.

JFA Purple Orange asserts the assumption that group homes are the only viable or realistic accommodation option for people living with disability has been debunked. The Individual Supported Living research project (led by Curtin University) found that "adults with all levels of support need can be supported to live in an (Individual Supported Living) arrangement."<sup>8</sup>

There are many viable alternative accommodation options to group homes for people living with disability, some of which have been formally recognised by the NDIS and called 'Individual Living Options'. The NDIS website lists four types of Individual Living Options:

- Co-Residency support resides full time or part time in the participant's home
- Host Arrangements participant resides full time in the home of a non-related host who provides support
- Living Alone support is provided in the home of the participant in a variety of ways
- Living Together participant lives with other people of their choice and receives support<sup>9</sup>

<sup>&</sup>lt;sup>8</sup> Cocks, E. and Thoresen, S. 2017, Individual Supporting Living Options Manual 2<sup>nd</sup> Edition, Curtin University of Technology, School of Occupational Therapy and Social Work.

<sup>&</sup>lt;sup>9</sup> NDIS, Individual Living Options, accessed on 12 May 2020 at <u>https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/housing/individual-living-options</u> 17

What is important to understand about these options is that they represent an *individual* living option, not an *independent* living option. It is very rare for someone to live an independent life free of support, whether that be informal or formal support. Therefore, NDIS planners must contemplate how a combination of both formal and informal supports could assist a person to achieve the individual living arrangement they want.

Recommendation 2: The role of informal supports in assisting a person to achieve their individual living preferences should be considered in the NDIS planning process.

### 4.1. The role of informal supports

The heightened need for support is a frequently touted reason for a person living with disability to move into or remain in a group home. However, these conversations often focus only on the availability of paid supports and the most efficient way paid supports can be delivered. Therefore, the important role informal supports can play in the lives of people living with disability has previously been ill considered in planning processes about accommodation options. Informal supports, such as helpful neighbours or circles of support, can assist a person living with disability to achieve a living arrangement based on their individual needs and aspirations.<sup>10</sup> Informal supports can also play a crucial role in helping a person living with disability feel connected to their community and can provide a reliable safety net in the event paid supports fail or, as has been experienced recently, a crisis such as COVID-19 emerges. Since the physical distancing measures imposed as a result of COVID-19, mainstream and social media have been littered with examples of neighbours performing acts of kindness for one another. In South Australia the <u>Neighbours Helping</u> Neighbours Facebook group was set up to help older South Australians access essential

<sup>&</sup>lt;sup>10</sup> Belonging Matters, a Victorian-based advocacy organisation for people living with disability and their families publishes a video series called <u>Talks That Matter</u> which showcase a number of real-life examples of people living with disability being supported into individual living options (such as living with a flatmate). 18

supplies at their home through donations from people in their local areas. As physical distancing measures have eased and food/grocery shortages have been resolved this Facebook group is sadly no longer active. JFA Purple Orange believes there is an ongoing need in the community for organic, freely given relationships between neighbours as a means to promote inclusivity and to help safeguard people experiencing vulnerability, because whether we are in the midst of a pandemic or not, paid supports alone are not an antidote to harm, loneliness or inadequate care.

Recommendation 3: Federal, State and Territory Governments should invest in projects that advance inclusive neighbourhoods and promote informal supports as a means of safeguarding people living with increased vulnerability.

### 4.2. Investment in Social Capital

The nature and extent of our connectivity to other people represents Social Capital, and is an asset that can be used to advance a person's life chances. The Model of Citizenhood Support proposes two main aspects of Social Capital: Connection and Fellowship.

Connection refers to the transactions that happen between people. Fellowship on the other hand refers to the depth of those transactions. Fellowship can range in depth from the pleasant familiarity of chatting to the same checkout operator during our weekly shop, or a regular cuppa with the neighbours, acquaintanceships, friendships, and close relationships. But none of these fellowships can grow or be sustained without the initial and subsequent connections shared by the people involved. Social Capital can be considered to be low if the person has few connections and relationships. The consequence of low Social Capital is isolation and loneliness, and in extreme cases, heightened vulnerability of abuse and neglect.

The circumstances of the recent death of South Australian Ann Marie Smith serve as a tragic and powerful reminder of the potential consequences for a person with low Social Capital and where their only relationships in life are those filled by paid service providers. Multiple

lines of inquiry have been established as a result of Ms Smith's death, including a police investigation, the establishment of the Safeguarding Task Force by the South Australian Government, the appointment of the Hon Alan Robertson SC by the NDIS Quality and Safeguards Commission to conduct an independent review of the circumstances around Ms Smith's death and a coronial inquiry.

As these processes continue to unfold, and more information about Ms Smith's life come to the fore, public discourse about her death is beginning to change. Now that the understandable desire to seek justice for Ann Marie by holding accountable those responsible for her paid care has been expressed, and reviews of the registration and oversight of NDIS providers are underway, some people are beginning to contemplate what role we as members of the community could play in keeping people safe. This is because formal oversight systems can fail, rules can be broken and laws and regulations in and of themselves cannot keep us all safe all of the time. But warm and compassionate human contact, such as from neighbours being neighbourly, mean more people are likely to notice and to ask questions if a vulnerable neighbour seems different or has not been seen for a while. This is a powerful natural safeguard that can help keep someone safe. These same safeguards are relevant regardless of whether a person lives alone or whether they live in a group home. No one should be in a position where paid, formal supports are the only thing that stands between them and a life featuring violence, abuse, neglect and exploitation.

JFA Purple Orange believes formal supports, such as SIL providers and disability support workers, have a fundamental obligation to uphold and advance their clients' Social Capital. This means they must carry out their endeavours in ways which help maintain, and do not inadvertently undermine, the person's social connections. Formal support providers should also be mindful of the role they can play in supporting a person to advance their Social Capital by organising its supports in ways which continuously present opportunities for the person to make new connections in mainstream community life, and to maintain and deepen connections so that true mutual fellowship emerges. Similarly, this NDIA has a role to play in identifying when a participant may be experiencing low Social Capital due to heavy reliance on paid formal supports and supporting that participant to make more informal social connections.

Recommendation 4: As part of every Plan review, the NDIA should examine the Social Capital of Scheme participants to identify where increased reliance on formal supports may put them at risk of experiencing violence, abuse, neglect or exploitation. Measures should then be put in place to support the participant to make and strengthen connections in mainstream community life.

# 5. Question 7: Are you aware of the use of restrictive practices in group homes?

In this submission we have used the definition of restrictive practices offered by the Government of South Australia:

Restrictive practices refer to any practice, device or action that removes or restricts another person's freedom, movement or ability to make a decision. This includes detention, seclusion, exclusion, aversive restraint, chemical restraint, physical restraint, mechanical restraint, environmental restraint and psycho-social restraint. Restrictive practices do not include therapeutic or safety devices/practices, where the device or practice is being used for its intended purpose and the person is not resisting or objecting to its use.<sup>11</sup>

Restrictions can include (but are not necessarily limited to):

 mechanical, such as devices that limit a person's movements (and this includes the removal and/ or disengagement of mechanical supports that assist the person's movements)

<sup>&</sup>lt;sup>11</sup> SA Government DCSI Safeguarding People with Disability Overarching Policy, DIS/366 – POL-SER-002-2013 21

- **seclusion**, such as the sole confinement of a person at any time in any room where the doors and windows cannot be opened by that person
- **environmental**, such as preventing free access to all parts of a person's environment or house (for example locking the refrigerators)
- **social**, such as the imposition of sanctions that restrict the person's access to relationships/opportunities they value
- **chemical**, such as medications that blunt the person's emotions, cognition, and motor activity
- physical, such as holding or 'pinning down' by another person
- **psycho-social restraints**, such as power control strategies which might include threats, intimidation, fear, coercion, discipline, or retaliation
- organisational, such as excluding the person from activities, and restrictions to the person's choice
- communication restraint, such as switching off someone's communication device
- decision making restraint, such as failing to provide options for supported decision making

During discussions between JFA Purple Orange and family members of people living with disability have described some of the experiences their loved ones have had with restrictive practices while living in group homes. One mother described how when her adult son returned to live in the family home after living in a group home he would go into the bathroom to drink water from the tap at night. This was a habit he developed in the group home because the kitchen was always locked overnight and the bathroom was the only place her son was able to get a drink of water. This is an example of an environmental restrictive practice.

During another conversation, one person recalled how their family member who lives with disability was subjected to decision making restraint, particularly around meal times and activities on offer. For example, a group home staff member would ask "do you want your dinner at 4:30pm or 5:00pm?" or say "you want to go to the park today don't you?". In both

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instances the family member was not offered genuine choice to support their decision making. Instead, the support worker was framing the choice around their own preferences.

Research close to two decades ago highlighted that people living with intellectual disability based in group homes were more likely to be exposed to more restrictive management practices than people living institutional settings, within which at the time restrictive practices were used widely.<sup>12</sup> Similarly, more recent research conducted within an NDIS context has recognised that whilst small group homes have been the primary model of service to support people moving from institutions or family homes there are still many shortcomings and potential risks to this model.<sup>13</sup> For instance, it has been stated by Australian researchers that residents in group homes are being treated in ways that would not be acceptable for other people, including being punished for sets of behaviours they may have little control over.<sup>14</sup> Importantly, research focusing on how to address issues within group homes and altering the culture to support better outcomes for occupants has highlighted several useful points. In particular, it has been suggested that organisations providing support staff within group homes develop front-line supervisors' team leadership skills and aim for staff members' shared ways of working to be directed towards supporting resident well-being. In this way, training and interventions that improve these dimensions of culture can potentially contribute to greater levels of engagement and community participation of people who live in group homes.<sup>15</sup>

However, in acknowledging that restrictive practices are often imposed by people in paid support roles, JFA Purple Orange recognises that informal supports play a crucial role in

<sup>&</sup>lt;sup>12</sup> Emerson, E. (2004) Cluster housing for adults with intellectual disabilities, Journal of Intellectual & Developmental Disability, 29:3, 187-197, DOI: <u>10.1080/13668250412331285208</u>

<sup>&</sup>lt;sup>13</sup> Bigby, C. and Beadle-Brown, J., 2016. Culture in better group homes for people with intellectual disability at severe levels. Intellectual and Developmental Disabilities, 54(5), pp.316-331.

<sup>&</sup>lt;sup>14</sup> Fisher, K. R., Purcal, C., Jones, A., Lutz, D., Robinson, S. & Kayess, R. What place is there for shared housing with individualized disability support? 1 Jan 2019, In: Disability and Rehabilitation. 23, p. 1-9.

<sup>&</sup>lt;sup>15</sup> Humphreys, L., Bigby, C. and Iacono, T., 2020. Dimensions of group home culture as predictors of quality of life outcomes. Journal of Applied Research in Intellectual Disabilities. 23

safeguarding against their inappropriate use against people living with disability. Informal supports are examples of the concept that people living with disability are more likely to be safe when they are actively involved with their family and the community. The things that make people safe can be seen as the same things that are needed to have 'a good life'. For example, caring relationships and enhanced opportunities for participation in mainstream community life. We therefore believe that freely given relationships are the greatest protections or safeguards for people living with disability, and this is an important factor in considering the use of restrictive practices within group homes.

### 6. Conclusion

JFA Purple Orange is grateful for the opportunity to respond to the Commission's Issues Paper on Group homes. We hope that our submission is of help to the Commission as it completes what role, if any, group homes should play in providing accommodation for people living with disability in the future. Please do not hesitate to contact us if you would like to discuss any of the ideas raised in this submission further.

24

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