



**Submission made by Julia Farr  
Association**

**Revision of the National Standards for  
Disability Services**

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**1. PLEASE BRIEFLY DESCRIBE A LITTLE BIT ABOUT YOUR ORGANISATION AND YOUR PROFESSIONAL ROLE.**

The Julia Farr Association and its predecessor organisations have been involved with the disability community for over 130 years. The organisation holds that the following values should inform policy development in this area:

- **Personal authority** – where people living with disability have and exercise control over the decisions in their lives;
- **Social inclusion** – where people living with disability are included as active citizens in the life of the wider community;
- **Capacity-building** – where people living with disability, through access to experiences and support, are growing their capacity to enjoy active lives of choice. This also includes the wider community growing its capacity to be inclusive and supportive of people living with disability.

The Julia Farr Association is an independent, non-government entity based in South Australia that fosters innovation, shares useful information, and promotes policy and practice that support people living with disability to access the good things in life. We are not a service provider – we deliver research, evaluation and information services that are anchored upon the stories shared by people living with disability, family members and other supporters. As such, we feel we are in a good position to offer comment and analysis without vested interest.

**2. PLEASE TICK THE GROUP THAT BEST DESCRIBES YOU/YOUR ORGANISATION FOR THE PURPOSES OF THIS SUBMISSION.**

- Representative from an advocacy organisation or peak body

**3. DO YOU WORK AS A SERVICE DELIVERER, FOR GOVERNMENT OR FOR AN ADVOCACY OR PEAK BODY?**

- Yes

**4. IF YOU WORK AS A SERVICE DELIVERER, FOR GOVERNMENT OR FOR AN ADVOCACY OR PEAK BODY, WHAT IS THE NAME OF YOUR ORGANISATION?**

- Julia Farr Association

**5. IS YOUR SUBMISSION AN ORGANISATIONAL RESPONSE OR A PERSONAL VIEW?**

- Organisational

**6. ARE YOU WILLING TO HAVE YOUR SUBMISSION MADE PUBLIC?**

- Yes, with the name of my organisation

**7. PLEASE USE THIS LIST TO MARK THE TYPES OF SERVICES YOU PROVIDE, PLAN FOR OR RECEIVE.**

- Other (please specify) – The Julia Farr Association delivers research, evaluation and information services that are anchored upon the stories shared by people living with disability, family members and other supporters.

**8. to 13. Relate to a person living with disability completing the submission**

**14. WHAT STATE OR TERRITORY DO YOU LIVE OR WORK IN?**

- South Australia

**15. WHAT IS THE POSTCODE/S OF THE AREAS YOU SERVICE OR LIVE IN?**

- Australia wide

**16. HOW WOULD YOU DESCRIBE THE GEOGRAPHIC AREA YOU LIVE OR WORK IN?**

- Urban/metropolitan area

***Section A: Your knowledge of the National Standards for Disability Services. This section is about you or your organisation's knowledge of the NSDS.***

- ***What do you know about the NSDS?***
- ***What is their purpose? Who uses them and how?***

The NSDS were implemented in 1993 for the purpose of ensuring Commonwealth and State funded disability services provide people living with disability with opportunities to participate in their community and achieve positive outcomes.

The NSDS provide the framework for disability service provision expectations and focuses on ensuring services are addressing the principles and objectives of Commonwealth and State/Territory legislation including:

- To assist people to integrate in the community;
- To assist people to achieve positive outcomes, such as independence;
- To promote in the community a positive image of people and enhance their self-esteem. (Taken from the *Commonwealth Disability Services Act 1986*)

## **Section B: Ideas and issues covered in the NSDS.**

**This section is about what should and should not be included in the NSDS.**

- *To what extent do the NSDS cover everything they need to?*
- *What ideas or concepts are missing or included by not needed?*
- *How would you like to see the NSDS changed?*

### **1. CITIZENS FIRST AND FOREMOST**

The most important contextual point we can make is that people living with disability are citizens first and foremost, and as such belong at the core of our communities.

This means that the NSDS must have proper regard for the rights of people living with disability to live active, inclusive lives in community, and to promote and uphold this citizenship in the design and commissioning of disability services.

Further, this means that commissioning of service arrangements must ensure that people living with disability have genuine opportunity to access, and maintain, presence within the local community, and to enjoy active participation in mainstream community life alongside non-disabled people.

To provide for anything less would mean that our disability service settings are undermining the right of people living with disability to a decent, valued life.

#### **Recommendation 1**

*The Julia Farr Association recommends that the standards demand and uphold the place of people living with disability as valued citizens at the core of our communities.*

#### **Recommendation 2**

*The Julia Farr Association recommends replacing the term 'service' with the term 'support' throughout the standards.*

This may seem like a small issue but our opinion is there is a fundamental difference. The term 'service' tends to be agency-centric and can set the scene for the service to be an end in itself – “*We've provided a service, job done*”. The term 'support' is person-centric, and sets the scene for arrangements that are a means to an end, which is a lifestyle of choice and citizenship.

#### **Recommendation 3**

*The Julia Farr Association recommends changing the name of the standards to reflect the valued status of people living with disability in the delivery of the supports they need. We believe the name of the standards should be:*

- **NATIONAL STANDARDS FOR SUPPORTING PEOPLE LIVING WITH DISABILITY (NSSPLWD)**

In support of our assertion, we will use the acronym NSSPLWD throughout the remainder of this document.

## **2. THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES SHOULD UNDERPIN THE STANDARDS (NSSPLWD)**

The current National Standards for Disability Services acknowledge that “[p]eople with a disability have the same rights as other Australians” (National Standards for Disability Services, p. 3), and highlight that the standards support these rights. However, the Julia Farr Association believes there needs to be a greater emphasis on promoting and protecting the fundamental rights of people living with disability in the standards.

We believe that the UN Convention on the Rights of Persons with Disabilities<sup>1</sup> (UN Disability Convention) should underpin the NSSPLWD to ensure that Commonwealth and State/Territory funded disability services are meeting Australia’s obligations under the Convention.

The UN Disability Convention’s general principles in Article 3 highlight how closely the Convention aligns with the standards.

### ***Article 3 – General Principles***

*The principles of the present Convention shall be:*

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;*
- (b) Non-discrimination;*
- (c) Full and effective participation and inclusion in society;*
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;*
- (e) Equality of opportunity;*
- (f) Accessibility;*
- (g) Equality between men and women;*
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*

### **Recommendation 4**

*The Julia Farr Association recommends aligning each standard with the relevant section(s) of the UN Disability Convention to reinforce the importance of promoting and protecting the fundamental rights of people living with disability.*

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<sup>1</sup> United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

### **Section C: Purpose of the NSDS.**

**This section is about what you or your organisation thinks is or should be the intention of the NSDS.**

- ***What do you see as being the purpose of the NSDS?***

The Julia Farr Association believe that the key purpose of the NSSPLWD should be to provide a compelling, accountable framework for supporting people living with disability to move into lives of active citizenship. In this sense, the NSSPLWD are about standards for *citizenship support*. We refer the National Quality Framework Project Team to the Julia Farr Association 2010 publication '*Model of Citizenship Support*' attached which sets out five domains for support that will lead people into citizenship. In each case, the domains provide a good context for setting standard. The Julia Farr Association would be very happy to offer example draft standards relating to each of these domains, and associated external audit arrangements.

### **Section D: Words/language in the NSDS.**

**This section is about the appropriateness and relevance of the words and language used in the NSDS.**

- ***What do you think about the words (language) used in the current NSDS?***
  - ***Please give examples of the language you see as appropriate or inappropriate.***

#### **1. OMIT THE USE OF THE TERM 'CONSUMER'**

The Julia Farr Association believe that the use of the term '**consumer**' throughout the document implies that people living with disability are recipients of services and not key contributors to how services are provided. We believe people should have the control and choice over what and how services are provided.

#### **Recommendation 5**

*The Julia Farr Association recommends that the term '**consumer**' be replaced by '**people living with disability**' and that the glossary definition be removed.*

#### **2. OMIT THE USE OF THE TERM 'LEAST RESTRICTIVE WAY' IN THE STANDARDS**

The current reference to 'least restrictive way' in the standards:

*Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.*

The current glossary definition of 'least restrictive way':

*'Least restrictive way' means the provision of services which are appropriate to people's needs, while allowing them as much freedom of choice, independence and opportunity as possible.*

We acknowledge that the definition of '**least restrictive way**' provided in the standards glossary does not imply that people living with disability experience restrictions. However, when it is referenced in the Individual Needs standard it sets a context of restriction. In this way, the national standards, however unintentionally, reduce the horizon of what is possible in people's lives.

Instead of focusing on the notion of *restriction* the standards should focus on the notion of *safeguards*. Where restrictive practice is service-focused, and with an emphasis on managing a 'problem', *safeguarding* is person-focused and demands careful attention to rights-based lifestyle goals such as choice and citizenship and the support that someone with heightened vulnerability might need to succeed in this.

### **Recommendation 6**

*The Julia Farr Association recommends the term 'least restrictive way' be removed from the standards and that instead there be a standard that asserts the notion of safeguarding, as follows:*

- *Each person living with disability is supported in a way that is designed to meet his or her individual needs and personal goals, and with the thoughtful use of safeguards where these are needed to help ensure the person is successfully moving towards a life of choice and citizenship.*

## **3. CHANGING THE FOCUS OF THE STANDARDS TO EMPHASIS THAT PEOPLE LIVING WITH DISABILITY ARE VALUED CITIZENS FIRST AND FOREMOST**

We believe that the current standards do not provide an adequate context for the provision of supports "that help ensure that people with greater degrees of vulnerability are supported to achieve the activities and status of citizenship and in keeping with each person's lifestyle choices"<sup>2</sup>, and that the domains within the *Framework of Citizenship Support* offer a more compelling framework for thinking about the standards by which people are supported.

### **Recommendation 7**

*Therefore, the Julia Farr Association recommends that the NSSPLWD use the following Framework for Citizenship Support<sup>2</sup> to ensure that people living with disability are valued citizens first and foremost:*

#### **1. Carrying a Personal Vision**

- *The vision is about the articulation, affirmation and realisation of a preferred lifestyle, reflecting the person's individuality, ordinary life goals, and opportunity to participate as a citizen.*

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<sup>2</sup> Julia Farr Association 2010, *Model of citizenship support: Discussion paper*, Julia Farr Association, Unley, South Australia, p. 4. SEE ATTACHED

## **2. Asserting a citizenship-based approach to service systems**

- *If a person needs support to be an active citizen, that support must happen in a way that upholds and reflects the person's personal authority, citizenship, human rights, and potential.*

## **3. Access to supported information**

- *Citizens need information to make choices, to assess risk, to test ideas, and to grow capacity. Good information makes it more possible for the person to make an informed choice.*
- *Supported information refers to the resourcing of information so that it is accessible and understandable, and soundly relates to the person's best interests (as typically articulated by the person) and in any case incorporating citizenship, protection of human rights, and upholding the person's potential.*

## **4. Access to material resources**

- *People need to be able to access material resources that enable and reflect active citizenship, that are reasonable in terms of 'levelling the playing field' and achieving a fair go. These material resources include both personal assistance (through mechanisms such as Individualised Funding<sup>3</sup>) and mainstream community resources.*

## **5. Fellowship and connection**

- *Society is built on the ideas of interdependency and association. Through such association, rich and trusting relationships emerge that help sustain and grow us on life's journey.*
- *Support agencies therefore need to ensure that support arrangements consistently create opportunities for people living with disability to move into fellowship and connection with non-disabled people.*

### **Section E: Using the NSDS in practice.**

**This section is about the relevance of the NSDS to practical experience.**

- ***How relevant do you find the NSDS to your experiences? You can use specific examples.***

As evidenced by "Shut out: The Experiences of People with Disabilities and their Families in Australia"<sup>4</sup>, a National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council in 2009, people living with disability are not currently being supported into lifestyles that reflect the current standards, notably individual needs, decision-making and choice, participation and integration and valued status. In which case, the standards have not been successful in shaping the support arrangements, and therefore have little connection to the lived experience of people living with disability in Australia.

<sup>3</sup> Individualised Funding is also known as Self-directed Funding, Individualised Budgets, Personalised Budgets, Consumer Managed Care and others.

<sup>4</sup> National People with Disabilities and Carers Council 2009, *Shut out: The experiences of people with disabilities and their families in Australia*, Commonwealth of Australia, <[http://www.fahcsia.gov.au/sa/disability/pubs/policy/community\\_consult/Documents/NDS\\_report.pdf](http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Documents/NDS_report.pdf)>.



We therefore believe the present revision of the standards is urgent and timely, and is a critical opportunity to establish a new paradigm of expectations about how people are supported.

### **Section F: Reviewing the NSDS.**

**This section is about other practical considerations relating to reviewing the NSDS.**

- ***To what extent do you think the NSDS are easy to find and use for different groups (eg people with a disability, service providers)?***

There are always opportunities to improve the accessibility of such materials so that the disability community is better informed about their meaning and intent.

However, the central issue is one of compelling accountability, and we are not convinced that the current standards, in their articulation and placement, are having any significant impact on the extent to which people are supported well.

We believe that by holding support agencies genuinely accountable for outcome-based standards such as in the *Framework of Citizenship Support*, this will drive the visibility and utility of these standards.

- ***How important do you think it is for the NSDS to be consistent with other policies, legislation and conventions?***

This is of central importance. Refer to SECTION B regarding the importance of ensuring the standards align with the UN Disability Convention.

### **Section G: Overall effectiveness of the NSDS.**

**This section is about what works well and what does not work well in the NSDS.**

- ***What do you think works well with the current NSDS?***

- The current standards set some helpful markers for disability support, but there are some huge omissions which critically undermine the utility and impact of the standards.
- The Julia Farr Association is not convinced that there is anything like a sense of compelling accountability for supporting people well.

- ***What do you think does not work well with the current NSDS?***

Although the current NSDS highlight the importance of involving and consulting with people about services, the Julia Farr Association believes that there is not enough emphasis on people living with disability being at the centre of support arrangements. Therefore, we believe the standards should highlight the importance of supports being person-led.

## **Section H: Feedback on the assessment against the NSDS.**

This section is about the issues involved in and process of assessing performance on the NSDS.

- ***What should governments, service providers and service users do to check that the NSDS are met? How should this information be used?***

- Design and run authentic outcome-based metrics that in turn impact on the future involvement of support agencies in people's lives.

- ***How can people with a disability and their family members/carers best provide feedback on service provider performance against the NSDS?***

- By moving into Individualised Funding<sup>3</sup> arrangements for all disability support, people living with disability are in control and can provide feedback, and act on it, in the same way as any other citizen in a customer role.

## **Section I: Meaning of each NSDS.**

This section is about the meaning that each current NSDS has for those using and experiencing them.

- ***Please enter up to three words or key phrases about what each NSDS means to you.***

The Julia Farr Association chooses not to comment, given our view that the standards be replaced by domains such as those in the *Framework of Citizenship Support*<sup>2</sup>

## **Section J: Other comments.**

This section provides space for any other comments you may have about the NSDS and how they should be revised.

- ***Do you have any other comments about the NSDS or about how they should be revised?***



# Model of citizenship support

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Discussion paper



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## 1.0 Purpose

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The purpose of this paper is to outline a new framework for assisting vulnerable people into lives of citizenship.

## 2.0 Initial definitions

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*Citizenship* refers to an active lifestyle that has the prospect of fulfilment for the person concerned. Such a lifestyle is one where, as part of a personally defined set of lifestyle choices, the person is in and part of their local community, contributing and growing through involvement in meaningful valued activities, and participating in a network of relationships characterised by acceptance, belonging and love.

*Citizenship Support* refers to an intentional set of arrangements that help ensure that people with greater degrees of vulnerability are supported to achieve the activities and status of citizenship and in keeping with each person's lifestyle choices.

## 3.0 Background

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It is hard if not impossible for each one of us to meet all of our personal needs and wants directly through our own skills and efforts. It is a rare person who has the extraordinary range of capacity to undertake their own dental work, maintain a market garden, construct a house, make clothes, and grow the cotton to make those clothes, and so on.

In this sense we all have a degree of vulnerability, and we manage this by living a life characterised by interdependence, where we interact with other people in our world to fulfil a broad canvas of needs and preferences, ranging from fresh vegetables to primary healthcare, from artistic expression to blocked drains, from borrowing the lawnmower to minding the kids. From such interactions, a layered tapestry of relationships emerges, and this is one of the hallmarks of a truly rich life.

This broad range of transactions and encounters, characterised by people being sometimes in giving roles and sometimes in receiving roles, is part and parcel of citizenship.

Some people are born with, or acquire, physical or intellectual impairments that bring with them greater vulnerability, and to a point where it becomes very hard to move into habits of citizenship without assistance. This can also be true for people who are born, or otherwise move into, unrelenting lifestyles characterised by a poverty of resources/opportunities.

## 4.0 Imperative

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It is hard to find evidence that the current dominant form of disability support is demonstrably supporting people living with disability into citizenship. Just about every piece of research that JFA has published has shown that people living with disability are not being adequately supported into active lives. This was further emphasised by Shut Out, the Federal Government's analysis report of the consultation for the National Disability Strategy.

Meanwhile, pockets of more hopeful activity emerge in various places at various times. However, such initiatives and movements are not always formally reported and broadcast in a way that ties them into other related activities and considerations. As such, they are like individual jigsaw puzzle pieces that may have been well-described but without actually tying them into the other puzzle pieces nearby, those pieces further away, and the puzzle solution overall.

It also appears clear that in a number of jurisdictions, including South Australia, government is struggling to articulate a comprehensive model of disability support, in terms of its goals and its components.

Therefore, the following model outline marks the beginning of JFA's journey to take a lead in the articulation of a comprehensive model of support based on the goal of citizenship.

## 5.0 Framework for Citizenship Support – overview

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The Framework for Citizenship Support consists of five main themes:

1. Carrying a vision of personal citizenship
2. Asserting a citizenship-based approach to service systems
3. Accessing supported information
4. Accessing material resources
5. Building fellowship and connection

Each of these themes is outlined in the following sections, in each case including a brief summary statement together with an initial scan of the blockers and the enablers.

## 6.0 Carrying a Vision of Personal Citizenship

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### 6.1 Statement

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The vision is about the articulation, affirmation and realisation of a preferred lifestyle, reflecting the person, their ordinary life goals, and their opportunity to participate as a citizen.

## 6.2 Blockers

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Examples of issues that block this vision from taking shape and taking place include:

- Experience of service reciprocity that leads to passivity, fear, perverse incentives and horizon shrinkage.
- Poor access to information and advice
- poverty of personal material resources
- social isolation

## 6.3 Enablers

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Examples of enablers to assist this vision to take shape and take place include:

- Reclaiming the right to have a personal vision of choice and inclusion, on the same basis as other citizens
- Therapeutic response to people's previous trauma (healing the wounds)
- Building a strengths-based, affirming self-perspective
- Identifying preferences about those life elements to be preserved and those that could be different
- Making a plan
- Living the plan
- Marking the changes

## 7.0 Asserting a citizenship-based approach to service systems

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### 7.1 Statement

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If a person needs support to be an active citizen, that support must happen in a way that upholds and reflects the person's personal authority, citizenship, human rights, and potential.

### 7.2 Blockers

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Examples of issues that hinder or block this collaborative, rights-based relationship between the person and the service system, include:

- Bureaucratic service systems
- Subsuming of the person within a service organisation's vision for itself and its sustainability
- Poor recruitment, induction, training and support of support agency staff
- Agency leadership incoherence



- Learned culture patterns of object-based practice, which may include neglectful, abusive and oppressive practice
- Constraints created by block contracts and related mechanisms for allocating and distributing public funds for disability support

### 7.3 Enablers

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Examples of enablers to assist a collaborative, rights-based relationship between the person and the service system, include:

- Building within the ‘disability related organisations a deep awareness of people’s fundamental needs and rights
- Building habits of system co-design, based on the principle of, “*nothing about us without us*”
- Rebuilding an organisation’s value base and vision around personal authority and citizenhood
- Articulating organisational strategy that intentionally guides that organisation towards personalised support arrangements
- Redesigning organisational systems so that they uphold personal authority and citizenhood
- Recalibrating organisational skills in support of personal authority and citizenhood e.g. person-centred planning, person-centred support, person-centred mindfulness
- Auditing, recruiting and retaining staff in line with this
- Building organisational culture, by upholding personal authority, citizenhood, human rights, and potential
- Understanding and habitually applying safeguarding practice, as opposed to restrictive practice

## 8.0 Access to supported information

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### 8.1 Statement

---

Citizens need information to make choices, to assess risk, to test ideas, and to grow capacity. Good information makes it more possible for the person to make an informed choice.

*Supported information* refers to the resourcing of information so that it is accessible and understandable, and soundly relates to the person’s best interests (as typically articulated by the person) and in any case incorporating citizenhood, protection of human rights, and upholding the person’s potential.

## 8.2 Blockers

---

Examples of issues that hinder or block the carriage of supported information include:

- Information is unavailable or inaccessible
- Information is under-represented, misrepresented or otherwise misaligned with the personal's expressed personal authority, access to citizenship, protection of human rights, and upholding of potential.

## 8.3 Enablers

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Examples of enablers to assist carriage of supported information include:

- Openness, driven by the assumption that people need information to support active citizenship
- Framing information in accessible ways
- Hearing, and being guided by, the person's expressed personal authority
- Careful attention to citizenship, protection of human rights, and upholding of potential when preparing information to assist a person to make an informed choice
- Recognising that information is a two-way street, and can deliver benefits in terms of diversity and co-design
- Discerning information that is helpful not diverting

## 9.0 Access to material resources

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### 9.1 Statement

---

People need to be able to access material resources that enable and reflect active citizenship, that are reasonable in terms of 'leveling the playing field' and achieving a fair go. These material resources include both personal assistance and mainstream community resources.

### 9.2 Blockers

---

Examples of issues that hinder or block access to material resources include:

- Insufficient public funds, or access to those funds, necessary to critically support active citizenship
- Lack of critical control over how such funds are personally deployed
- Insufficient accountability in how public funds translate to outcomes in personal authority and citizenship
- Inaccessible community resources across some, many or all aspects of community life

## 9.3 Enablers

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Examples of enablers to assist access to material resources include:

- Entitlement-based individualised funding that is fair and equitable (for example, a National Disability Insurance Scheme, depending on how it's conceived and implemented)
- Accessible community resources
- Attitudes of welcome within community
- Habitual recognition and inclusion of people living with disability as valued citizens in the lives of our social institutions for example education, health, democracy and so on.

## 10.0 Fellowship and connection

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### 10.1 Statement

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Society is built on the ideas of interdependency and association. Through such association, rich and trusting relationships emerge that help sustain and grow us on life's journey.

### 10.2 Blockers

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Examples of issues that hinder or block the building of fellowship and connection include:

- Society classifies 'disability' as a problem, where 'difference' equates to 'separateness' and sometimes even carries assumptions of 'deviance'
- History of service systems that exclude and isolate people living with disability
- Ongoing wounds caused by the above

### 10.3 Enablers

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Examples of issues that hinder or block the building of fellowship and connection include:

- Development of a community awareness narrative, that focuses on diversity and rights
- Intentional building of networks and associations in people's lives
- Development of safeguards that help people to succeed in citizenship roles

## 11.0 Next steps

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Mindful that this framework will continue to evolve as it is developed in detail, the Julia Farr Association will use this model of citizenship support as the driving context for its strategic influence work for the next three years.

For more information about the Model of Citizenship Support, please contact the Julia Farr Association.





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