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Governance Arrangements

for individuals and families

Literature Review

Literature Review

Prepared by the NSW Department of Family and Community Services, Ageing Disability and Home Care.

Document approval

The *Governance Arrangements for individuals and families: Literature Review* has been endorsed and approved by:

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Glossary of Terms

ADHC	Ageing, Disability & Home Care, Department of Family and Community Services (NSW)
Corporate Entity	An organisation with recognised legal status in the state of New South Wales or throughout Australia that may:

- Enter into and enforce contracts, including the ability to hold, acquire and deal with property
- Sue or be sued
- Continue regardless of changes to membership.

Governance	Governance in this project refers to the decision making structures and processes that support the establishment and maintenance of the security of the shared living and resource pooling arrangements.
IASP	Individual Accommodation Support Package
Individualised funding	Funding set aside for an individual to pay for disability support services designed to meet his/her specific needs. Individuals choose how, when and who supports them.
NDIA	National Disability Insurance Agency
Intermediary	An organisation or entity which administers individual funding on behalf of the funding recipient
NDIS	National Disability Insurance Scheme
NSW	New South Wales
Package	General term for individualised funding packages provided by ADHC or another agency
SLF	Supported Living Fund

1 Introduction

> *'Secure affordable housing and appropriate housing is important for everyone, for vulnerable people it can make the difference between a good life and isolation, exclusion and premature death.'* (p.1)[1]
>
> *'…housing is for others, you and I have a home. Our home is our castle, it is where we are most intimate, sad, and joyful. It is where we want to be safe, yet free to do as we wish'* (p.1).[1]
>
> *'A home is a place of your own in the community where you are seen to belong.'* (p.2) [3]

This report presents:

- An overview of the policy context for the development of new accommodation and support arrangements in New South Wales (NSW) (Chapter 1);

- The methods used to undertake the literature review (Chapter 2);

- The findings from a targeted review of the literature relating to governance arrangements applicable to the establishment and operations of family-governed housing and support arrangements in NSW (Chapter 3-5).

The *Governance Arrangements for individuals and families: Literature Review* (the Review) is part of the *Governance Resource Kit: a tool for individuals and families* (the Kit) documentation.

1.1 The project

The *Governance Resource Kit: a tool for individuals and families* is intended to be used when two or more individuals choose to live together or in close proximity and to share funded supports. The Kit includes:

- Two literature reviews:
    1. Governance arrangements
    2. Resource pooling
- A resource pooling tool.

The objective of this literature review about governance arrangements is to identify best practice or emerging practice in family/informal support governance arrangements in shared support. The review includes:

- A description of key principles and guidelines that underpin self-governance and family governance (Chapter 3)

- Potential governance entities that could be considered by people with disability (people) and their families when establishing shared housing and support arrangements (Chapter 4)

- A proposed governance framework (Chapter 5).

1.2   Policy and project context

A number of factors have influenced the development of this project. These include (but are not limited to):

- NSW disability policy;

- The introduction of the National Disability Insurance Scheme (NDIS);

- The current transition from block funded supports to individualised funding to give people greater flexibility and control over their supports;

- The international and national focus on person-centred planning and practice; and

- Some NSW family groups being provided with housing funds (managed by community housing providers) and individualised funding to create their own housing and support options, for their sons and daughters, which they will govern.

1.2.1   NSW Policy

NSW recent and current policies include:

- *Stronger Together* (2006) and *Stronger Together 2* (2011)

- *The Living Life My Way Framework* (2013)[4]

- *Ready Together* (2013).[5]

Stronger Together was released in 2006 and *Stronger Together 2* in 2011. Key elements of *Stronger Together 2* include:

- An additional *'$2 billion in new funding for disability services from 2011-12 through to 2015-16'* including funding for an additional 47,000 people.

- Closure of large residential centres for people with disability by 2018 and increasing the supply of *'smaller contemporary accommodation, to give people a choice to live in a home-like environment, with more flexibility in their daily living routines.'* (p.15)[5]

- *'Expanding and reconfiguring supported accommodation options to provide more flexibility and a continued focus of building life skills and community participation'* (p.4).[6]

In the first two years 900 additional accommodation places were created.

During 2010-2012 a series of *Living Life My Way* consultations were conducted with 4,000 people with disability and their families. The consultations found that people wanted:

- Better access to information in a range of formats so that they can make informed choices
- Clear information about how they can use their Packages and a range of Package management options
- Greater control, choice and flexibility over their Packages, supports and lives
- A quality framework
- Assistance to implement the changes.[7, 8]

These consultations informed the development of *Ready Together* and the *Living Life My Way Framework.*

Ready Together and the *Living Life My Way Framework* aim to ensure that NSW is ready for the NDIS. Through these policies the NSW government is increasing the use of individualised funding through combining multiple funding streams into a single funding arrangement, directing funding into individualised support options, increasing use of supports that are culturally responsive, and reducing existing program constraints.[4, 5] More detail about individualised funding can be found in the *Governance Resource Kit: a tool for individuals and families - Resource Pooling Literature Review.*

Ability Links NSW, introduced as part of *Ready Together* and now operating in the Hunter region, is being rolled out state-wide from July 2014. The role of Ability Links NSW is to better connect individuals and families to local services and assist them to understand service provision expectations and arrangements. There is also support to assist the sector to transform their services and operations and a focus on increasing consumer capacity through initiatives such as *My Choice Matters* and the creation of *Living Life My Way* Ambassadors and Champions.

Other key policy activities include (but are not limited to):

- Introducing a person-centred service system that puts the person at the *'forefront of decision-making and choices that affect their lives'* (p.4)[6]
- Providing greater opportunities for people with disability to *'exercise choice, flexibility, and control over their supports, to build the skills necessary to plan and negotiate how their supports are delivered.'* (p.1) [4]
- Developing more inclusive communities and ensuring people can make informed choice.[9]

In NSW three key ingredients have been reported to assist individuals to live fulfilling and valued lives. These are:

- *'The right ideas*
- *Leadership to put those ideas into practice*
- *The right relationships.'* (p.20)[6]

1.2.2   The National Disability Insurance Scheme (NDIS)

The NDIS represents a significant shift in the way supports for Australians with significant disability are funded and provided. The NDIS has been described as the largest social policy change since the introduction of Medicare. Under the NDIS people who meet the eligibility criteria are allocated funds based on their support needs, goals and aspirations. The NDIS aspires to give participants greater control and choice over their supports and Packages. The supports provided are based on the NDIS legislation and rules.[10-12]

The introduction of the NDIS is accompanied by changes in the sector. It requires many changes to the way service providers operate - they need to be able to cost every service, create accurate accounts, market what they offer, have a more flexible workforce, etc. NSW was the first state or territory government to endorse the NDIS and is currently trialling the NDIS in the Hunter and Nepean/Blue Mountain regions. Under the full roll out of the NDIS NSW will cease providing specialist disability supports.[5]

1.2.3   Changing accommodation and support models

There are a number of factors that influence accommodation and support for people with disability. These include socio-demographics, affordability, housing supply and individual characteristics and support needs, etc. (Appendix 1: <u>Factors in Housing and Support</u>).

Traditional shared supported accommodation models in Australia have been block funded and managed (and often owned) by community service organisations or government departments providing the support.

There is evidence that some congregated settings may not always deliver the intended outcomes, or can become mini-institutions, where some people experience poor quality of life.[14-16]

The move towards individualised funding and the NDIS, with the focus on increased choice and control, and the decision to separate housing and support means that new accommodation options and governance arrangements need to be developed.

It is acknowledged that people accessing accommodation and supports that allow them to move out of the family home may encounter a range of challenges. Some of these include *'their confidence in their ability to live independently, the confronting concerns of family, friends and carers about their safety and survival, and the difficultly involved in securing flexible supports.'* (p.6)[17]

A fundamental element is ensuring that the decision to live with others and share supports is what each person wants. There are some guides available to assist people to work out what they want in regard to accommodation and support. These include (but are not limited to):

- My life, your life and our life: A guide for flat-mates, home-sharers and co-residents[18]

- The housing toolkit [19]

- My preferences exploration and planning[20]

- A guide to developing personalised residential arrangements[21]

- A place to call home[3]

- A home that is right for me: Valuing choice, evolving residential options.[22]

There are some Australian and UK websites that have useful information on self-directed supports. These include among others:

- WAIS (www.waindividualisedservices.org.au/),

- Pearls of Wisdom (www.pearl.staffingoptions.com.au/),

- Helen Sanderson and Associates (www.helensandersonassociates.co.uk/).

1.2.4   Person-centred planning and practice

Person centred planning and practice is an essential element of support arrangements and should also underpin the governance arrangements. Person-centred practice is discussed in more detail in the accompanying document (*Governance Resource Kit: a tool for individuals and families - Resource Pooling Literature Review*).

1.3   Summary

NSW has embarked upon a series of policies, strategies and initiatives to increase the use of individualised funding and to prepare the sector, individuals and their families for the NDIS. ADHC is currently working with two groups, Ryde Area Supported Accommodation for Intellectually Disabled (RASAID) and the Sutherland Shire Disability Accommodation Action Group (SSDAAG) that are developing their own accommodation and support arrangements.

2 Methods

This literature review identifies governance options available to NSW individuals and family groups wishing to establish their own option when two or more individuals choose to live together or in close proximity, and wish to share some of their funded supports.

2.1 Key questions

A number of key questions guided the search for relevant information in regard to the formal and informal governance arrangements that could be used in shared living and resource pooling options. The questions examined included:

- What are the various governance arrangements available to individuals and families residing in NSW who have individualised funding?
- What entities (for example, incorporations, trusts, etc.) can be established?
- What are the benefits, risks and limitations of these arrangements?
- What principles or guidelines support these arrangements?
- What do people need to know about these arrangements?
- How are disagreements or breakdowns in these arrangements managed?
- What are the key success factors?

2.2 Search terms

The following search terms were used alone and in combination across all searches:

- People: for example, disability/disabilities, individuals, families, people, person
- Funding: for example, support funds, individualised funding, individual support package, personal budget, combined, pooled, shared
- Support arrangements: for example, accommodation, housing, support, direct employment, support workers
- Jurisdiction: for example, Australia, New Zealand, England, United States of America, Canada
- Governance arrangements: for example, governance, arrangements, shared management, management, circles of support, families, trusts, Microboards[TM]
- Principles, guidelines, best practice.

2.3 Academic literature

Academic literature was sourced using academic search engines (for example, Medline, Cinahl, PsychInfo and PubMed). As this was a targeted literature review, it

was limited to articles published in the last ten years and preferably those in peer-reviewed journals.

2.4   Grey literature

As much of the lived experiences of people who use these arrangements are documented in the grey literature, Google Scholar and Google were used to source relevant reports, presentations and websites of jurisdictions and/or groups or agencies which have developed more individualised support options and/or pooled support arrangements.

Substantial materials relating to corporate and governance structures were found in the grey literature. Fair Trading NSW, a division of The Department of Finance and Services, is the primary source of information for community based organisations in New South Wales – including arrangements that may facilitate pooled support arrangements in NSW. Fair Trading NSW publishes a significant amount of this information on www.fairtrading.nsw.gov.au.

2.5   Limitations of the review

There are some limitations of this review. These include:

- As the resource Kit is for NSW family groups, the information relating to legal entities has been limited to those described by Fair Trading NSW.

- Some entities were excluded as:

    - Their purposes were not aligned with accommodation and support arrangements for people.

    - They had significant establishment costs and compliance burdens; for example, for the keeping and auditing of financial records.

These excluded entities are:

- Business structures - sole traders, partnerships and proprietary limited companies.

- Trust structures – including trusts, unit trusts, special disability trusts and protective trusts for the purposes of managing the personal wealth or assets of an individual.

- Corporate structures specifically related to the management of tenancy arrangements or ownership of property or other real estate (including owners' corporations in strata developments, the executive committees of community and neighbourhood schemes, residents' committees in retirement villages and residential park liaison committees in residential parks).

In reality, few examples of self-governance and family governance arrangements in shared supported living arrangements exist at this time.

To supplement the literature, six agencies or family groups were contacted. Of these:

- One was a group home for people with disability located alongside, or near, units for people with low incomes, or other people with difficulties securing mainstream housing. The Victorian Department of Human Services managed the vacancy process; and the surrounding units were managed by a range of different agencies depending on who was living there (for example, the Office of Housing).

- One was a house (which was used by a couple who provided 24/7 support in lieu of rent) and three units for people with disability, but the interviewee was reluctant to provide information about their governance arrangements.

- Two interviewees were reluctant to be associated with the housing models currently being developed as they believe that the evidence does not support cluster and congregated living arrangements.

- One service provider managed the individualised funding of nine people and provided support to them in their own homes, but only two shared support (they were siblings who lived in a two bedroom unit).

- Another has established an intentional community of ten units which includes three people with disability. The model includes co-tenancy arrangements.

2.6   Summary

This Chapter described the methods used to conduct the literature review. A number of search strategies were used to source relevant materials and included academic search engines, Internet searches and interviews. The limitations have been noted, but did not adversely affect the review.

3 Principles of Self Governance and Family Governance

3.1 Introduction

This Chapter explores the underpinnings and the key principles and guidelines relating to self-determination, self-governance and family governance.

3.2 Self-determination and governance

Enshrined in the *United Nations Convention of the Rights of Disabled Persons*, the *Living Life My Way Framework* in NSW, and disability legislation and policies, is the right of people with disability to have control over their lives and support, and to be central in decision making affecting their lives.[5, 24, 25]

Over recent decades there has been discourse in the international and Australian disability literature about empowerment, personalisation, self-determination, rights, and choice and control. Central to what in the UK is described as personalisation, is the acknowledgement that individuals' needs, strengths and preferences should guide decision making about their lives and supports. These preferences and decisions should then shape how services and supports are provided. Expressing preferences and making decisions requires access to good information about universal services and a focus on capacity building.[26]

There is a strong link between individualised funding and self-determination and the need for disability services to be provided in a manner that is consistent with *'freedom, authority, support and responsibility.'* (p. 4)[27]

Further, many also argue that risk-taking, trying out new things and learning from these experiences is also part of self-determination.[28]

Despite the potential benefits of self-determination, there are reports that choice has been curtailed by the insufficient range of services and the closure of some services.[29] Others noted that governments may have underestimated organisations' capacity to implement individualised funding and supports and over-estimated *'the capacity of consumers, families, and communities to manage resource thin situations.'* (p.416) This same author questions *'How many people or their families really want to, or are really capable of, managing all their supports? (p.417)* [30]

However, self-direction should not become a one-size fits all approach that assumes everyone will want to take full control over all arrangements. It can become complicated when individuals do not want to *'be the leaders in their own lives. Do we say they have to anyway? ... I hear again and again that people get tired and do not envision themselves being responsible for making their services work forever.'* (p.471-2)[31]

So it is important to acknowledge that there will be a wide variation in the extent to which any individual or group is willing to lead and participate in day-to-day governance activities.
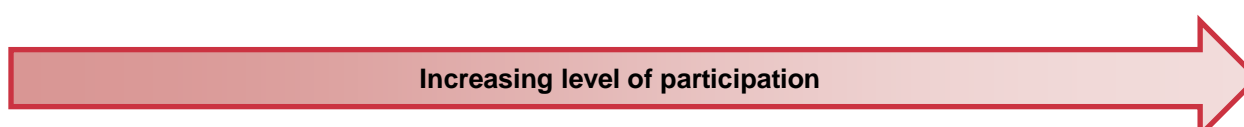
3.2.1   Resident participation in governance

Where the group or organisation has been established to support people with disability, it is important that processes are in place to ensure their involvement in the governance arrangements. Mechanisms need to be established that safeguard the voice of the individuals and that decisions are not made at a higher level that lose sight of their needs and wishes. Ways in which this is achieved include:

- In the Rougemount Cooperative[1], all members including the individuals with disability, are expected to attend all AGM meetings, etc.[32]
- Some incorporated association boards include elected members with disability.

As shown in Figure 3-1 below, participation in decision making can occur at many levels.

Figure 3-1: Levels of participation

Increasing level of participation				
*	**INFORM**	**CONSULT**	**INVOLVE**	**COLLABORATE**	**EMPOWER**

	INFORM	**CONSULT**	**INVOLVE**	**COLLABORATE**	**EMPOWER**
Goal	To provide balanced and objective information to help with understanding issues, alternatives and solutions.	To obtain feedback on issues, alternatives and decisions.	To work with a group to ensure their issues and concerns are understood and considered	To partner with members of a group in each aspect of decision making including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the individuals with disability and/or their family.
Process	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns, and provide feedback on how your input influenced the decision.	We will work with you to ensure your issues and concerns are directly reflected in the alternatives developed and provide feedback on how your input influenced the decision.	We will look to you for direct advice and innovation in developing solutions and incorporate your advice and recommendations in the decisions as much as possible.	We will implement what you decide.
Examples	• Fact sheets • Information books • Websites	• Surveys • Focus groups • Consultation meetings	• Workshops • Polling or a 'show of hands' to express preferences	• Advisory committees • Forums to build consensus • Participation in decision making	• Voting on issues • Decision making

* Adapted from the iap2 Public Participation Spectrum, International Association for public participation

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[1] The Rougemount Co-operative was formed by the Deohaeko Support Network in Canada as an intentional housing community for people with disability

3.2.2　Decision making

> *'The majority of people with disability are able to make and act on their own decisions in life. However, there are situations, particularly where people have a cognitive disability, complex support needs and/or communication difficulties, where people may need some assistance. The amount of assistance someone will need will depend on their personal circumstances'.* (p3)[2]

Day-to-day living requires an almost constant need to make decisions. This can range from the most minor decision (for example, what will I have for lunch; do I have time to get the washing out before it rains); to important decisions for individuals with Packages (for example, what can I purchase with my Package; which service provider will deliver the supports I want); to critical or life changing decisions that we all might face (for example, choosing to marry or buy a home).

Kendrick describes the six different levels of authoritative decision making that may reflect each individual's involvement. (Figure 3-2).[33]

This model will assist individuals, families and support workers to ensure that each person is supported to achieve the highest level of decision making.

Figure 3-1: Kendrick's levels of empowerment

Level 1
- The person does not make any substantive decisions about their service.

Level 2
- The person does not make any substantive decisions about their service, but the person is routinely informed about the decisions others will be making on their behalf.

Level 3
- The person is routinely asked to give advice, (for example, is consulted), by the actual decision-makers, about his/her personal service decisions.

Level 4
- The person begins to routinely make a significant minority of the substantive decisions that constitute their personal service. A significant minority, in statistical terms, might range from 25%-45% of key decisions.

Level 5
- The person routinely begins to make a significant majority of the substantive decisions that constitute their personal service. A significant majority, in statistical terms, might range from 55%-90% of key decisions.

Level 6
- The person is routinely making the vast majority of key decisions and they simply do not any longer believe that they have a meaningful empowerment issue.
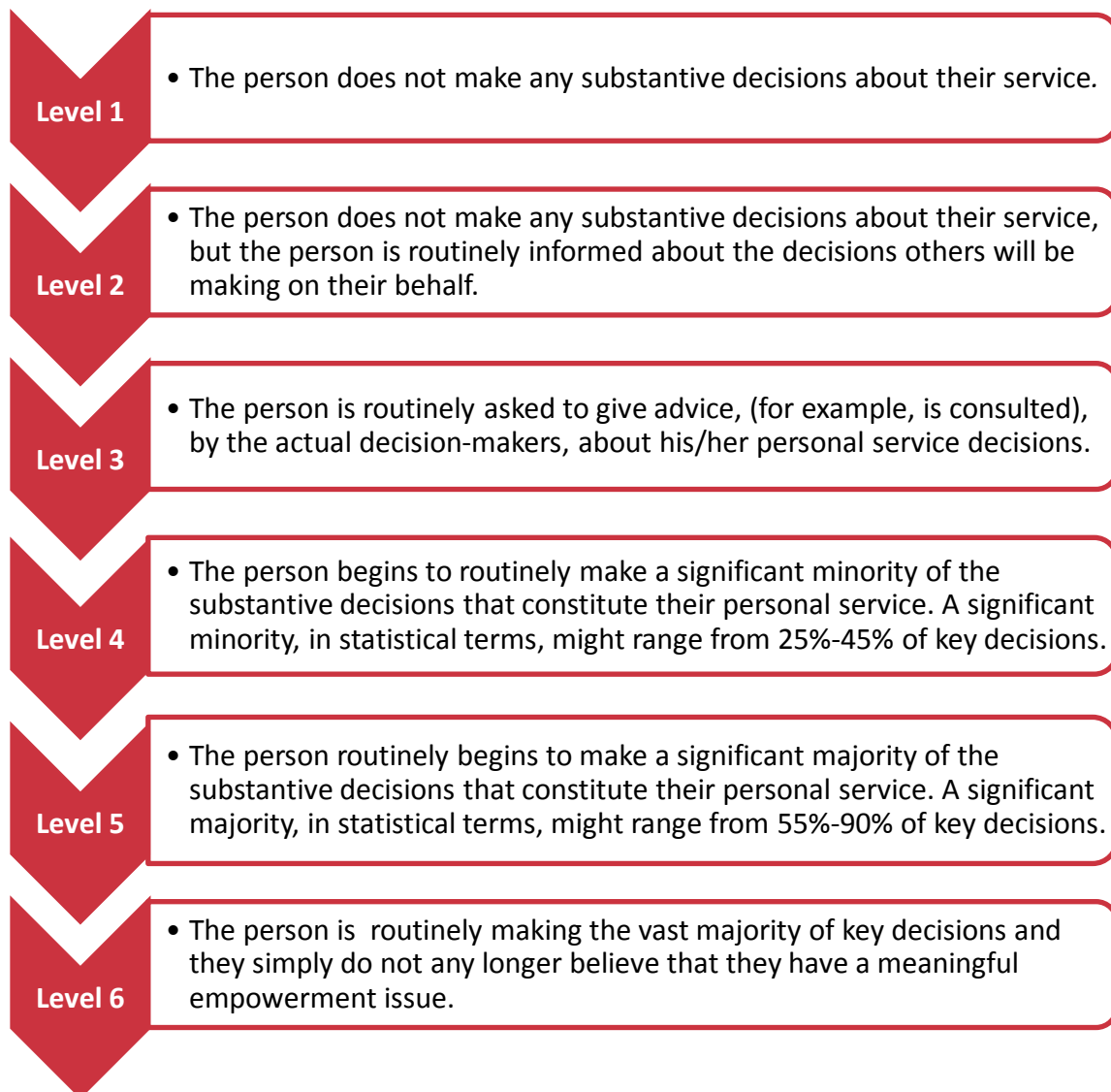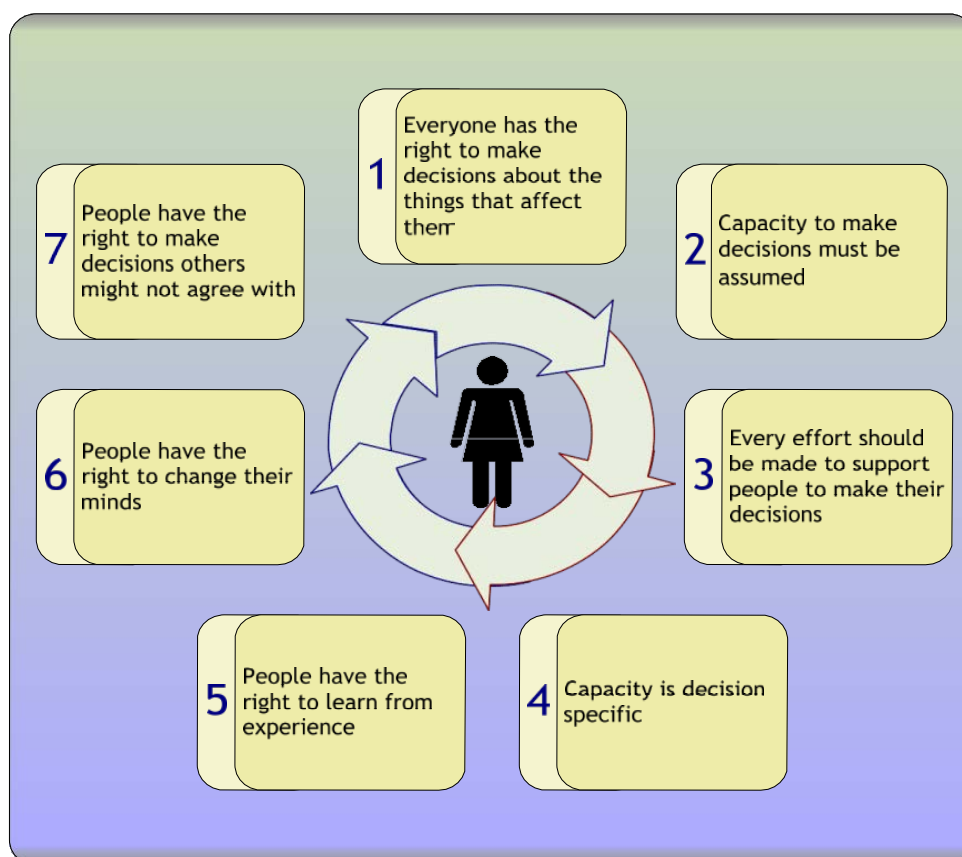
Figure 3-3: Principles to guide decision making for people with disability

The Victorian Department of Human Services recommends that the following principles form the basis for decision making for people with disability.[2]

Individuals and families may also seek information from service providers and other independent sources to ensure they have all the necessary information to make an informed decision. Some individuals will be capable of making independent decisions but others may require support, and in a smaller number of cases substitute decision making may be required.

Supported decision making involves receiving information in different formats and/ or involvement of family, friends, circles of support and advocates. When substitute decision making is required – decisions should be based on the *'best interests'* of the individual. In some situations (for example, the Victorian Civil and Administrative Tribunal) the term substitute decision making has a particular legal meaning. [2]

3.3 Family governance

In a formal or legal sense, family governance deals with issues related to a family business (such as a family trust). Governance in this project refers to the decision making structures and processes that support the establishment and maintenance of the security of the shared living and resource pooling arrangements.

In 2005, Margaret Ward identified ten guidelines for family governance.[34] These included:

- Understand the natural authority of family members

- Be clear about your vision and goals

- Be clear about what is family business and service business

- Solve problems quickly, locally and creatively

- Plan and be ready for spontaneous opportunities

- Have a plan for unexpected events and create appropriate safeguards

- Develop skills

- Work in right relationship

- Minimise administrative functions

Ward's work was partly drawn from Michael Kendrick's article *'The natural authority of families.'*[35] Kendrick reported that families and carers often felt overshadowed by professionals and bureaucrats. He suggests that *'it can sometimes be helpful to remember that families have a natural authority of their own which can go a long way to reducing this imbalance of power and authority...families need to appreciate this natural authority and be willing to act on it'.* (p 1)

Kendrick reminds us that:

- People should acknowledge the authority of families and their responsibility for ensuring the wellbeing of family members

- Family members have authority because usually they know the person most fully and for the longest period

- Family members typically love and care for the person more than others

- Families have a stake in outcomes

- Families are expected to advocate for their own family members

- The family is a witness to the performance of professionals and systems

- Family members bring a wide range of talents and experiences which can give them authority over many matters

- Families are often in the best position to see the person's life in its entirety

- Family members are often free of vested interests

At the same time, people, service providers and academics caution that there can be disagreement between the individual and their family about what they want and what is in the '*best interests'* of the person with disability. It is important that these issues are dealt with in a manner that acknowledges the different perspectives, but as much as possible the wishes of the person with disability should be respected.[36]

3.3.1 Family participation

Family governance models provide a solid basis for accepting the role of families in supporting their family member. In almost all cases, establishing a group living arrangement and sharing supports would be impossible without the vision and drive of families. Some cautions should also be addressed:

- Individuals will have differing views on their role, and the role of other family in making decisions about all aspects of the arrangement. To avoid disputes, the range of decisions that involve family members should be clarified during the establishment of the arrangement.

- Not everyone will have the same capacity to understand the various options and make a decision. This may be due to a range of reasons. For example, limited English skills, low literacy, lack of experience in 'making themselves heard', time constraints. The role of group decision making should be explored and a process established to ensure that each affected party is able to contribute their views prior to a decision being made.

- Families can get tired. This is particularly true where they have cared for their family member for a long time and have been involved in the search for funding and in establishing the arrangement. Family groups and individual members need to think carefully about how much involvement they want, or can manage, in the decision making about the long-term and day-to-day running of a particular arrangement. Difficulties may arise when some members want to be more hands on and engaged while others would prefer to be at 'arms-length.' These matters need to be resolved via establishing agreements.

3.4 Governance - key success factors

A range of success factors have assisted people and families to govern their accommodation and support models. These broadly relate to:

- Agreeing on and maintaining the vision, aim and key principles[32, 36]
- Developing clear roles and responsibilities
- Developing action plans and sharing the workload
- Perseverance, commitment and energy[32, 36, 37]
- Relationships[32, 36, 37]
- Effective process problem-solving and dispute resolution processes[32, 36, 37]
- Being prepared to take risks and try something new[32, 36, 37]
- Having sufficient funding[38]
- Focusing on building individual lives which include informal supports[32, 36]
- Succession planning.[37]

3.5 Key principles or guidelines

Whatever governance arrangements are developed, they need to uphold human rights and maximise the social benefits and opportunities to create cost savings.

The literature includes some guidance about the requirements for governance in supported living arrangements. Mansell et al. state:

'Increasingly the goal of services for people with disabilities is seen not as the provision of a particular type of building or programme, but as the provision of a flexible range of help and resources which can be assembled and adjusted as needed to enable all people with disabilities to live their lives in the way that they want but with the support and protection that they need. This is characterised by several features:

Separation of buildings and support
The organisation of support and assistance for people is not determined by the type of building they live in, but rather by the needs of the individual and what they need to live where and how they choose. High levels of support can be provided in ordinary housing in the community, for example.

Access to the same options as everyone else
Instead of, for example, determining that all disabled people must live in group homes, policy is framed around people having access to the same range of options as everyone else with regard to where they live and receiving the support they need wherever they may choose.

Choice and control for the disabled person and their representatives
Help is organised on the principle that the disabled person should have as much control as possible over the kind of services they receive, how they are organised and delivered, to fit in with the person's own aspirations and preferences. This means supporting people's decision-making to achieve the best balance between their wishes and society's responsibility for their care.

This approach is sometimes referred to as 'supported living' or 'independent living'. These services support people to live as full citizens rather than expecting people to fit into standardised models and structures.' (p.1)[39]

In summary, the following principles or guidelines are appropriate to underpin self-governed and family-governed accommodation and support arrangements.

Governance arrangements should be based on:
• Clear vision and high ideals about the outcomes that are being sought (and these are consistent with people's preferences)
• Ensuring all parties are well informed about all aspects of the arrangement and seek advice as needed
• Ensuring shared living and support reflects the individual's choice and preferences
• Persistence and creative problem-solving
• Ensuring that the workload reflects individuals and families expectations and preferences
• Mutual respect and trust
• Openness and each person being able to express their views and opinions
• Acknowledging diversity and each person's contribution
• Ensuring that people are actively engaged (and well supported if necessary) in any governance arrangements and decision making
• Clear agreements or contracts between parties
• Clear agreement of how they will manage a range of scenarios and risks (such as if someone leaves or has prolonged time away, incompatibility, fund mismanagement, delays in paying bills, dissatisfaction with a support provider, etc.)
• Each individual (person with disability or family member) choosing the level of participation they desire in the governance arrangements
• Clearly described roles and responsibilities
Housing and daily life arrangements should ensure:
• That the shared living and support arrangements reflect the person's choices and preferences
• Compatibility and connectedness
• That people accept that by choosing to live together and share some support, some compromises may be required
• Each individual's strengths, capacities are harnessed and developed
• That each person is supported in a way that upholds their rights and freedoms (i.e. in the least restrictive or intrusive manner) and reflects their support plan, goals and preferences

- That each person is encouraged to try out new opportunities (including taking some reasonable risks)

- That each person is able to furnish and decorate their personal space

Each person is:

- The primary householder (via ownership or tenancy) and all parties acknowledge that this is their home

- The key decision-makers in regard to:

  - Who the live with, how they live their lives, and who provides their supports

  - Leaving the arrangement if they choose

  - How much they wish to pool their supports or to share in meals, etc.

  - Who can enter their personal space

Each person has:

- A life of their own choosing

- A key to their home and is able to invite visitors to a meal, stay over, etc.

- A range of flexible supports (informal, community and paid supports) that meet their needs and preferences

- Involvement in daily life (for example, routines, chores, paying bills, etc.) and valued roles in the community

3.6   Summary

When considering self-governance or family governance in shared living and resource pooling arrangements, it is important to acknowledge that each individual or group may have differing expectations about their level of participation. As a result, there is no uniform approach to these arrangements. A set of principles garnered from the literature has been suggested as a guide.

4 Governance Arrangements

4.1 Introduction

Governance processes typically include specific activities that are required under relevant laws and regulations. These laws and mechanisms may be for an entire sector or specific to a particular group or organisation; for example, organisation specific rules and bylaws. Governance also includes less formal activities, such as agreed ways of acting.

Having an agreed way of governing can help everyone know what to expect from a group or organisation. Agreeing on how to manage issues before they arise may make it easier to reach agreement and to make decisions. Governance activities take time. For most groups, including incorporated associations and co-operatives, these activities are done on a voluntary basis. It is essential that all members have agreed about the level of commitment they are prepared to make in this regard.

Understanding the different models of governance available, and choosing the right one to meet the needs of an individual, group or organisation, is essential in ensuring the long-term sustainability of the arrangement.

4.2 Support Arrangements

In the traditional disability service model, the funding and supports are managed by one provider. Now, as more Australians are being allocated individualised funding (Packages), there are new ways for individuals to exercise choice and control over their support arrangements. These include options that:

- Are suited to individuals or to groups
- Allow individuals and families to arrange their supports
- Provide new Package management options
- Engage an agency to provide and manage the supports
- Directly employ and manage support workers
- May range from groups with no formal structure to options that establish a legal entity.

For example, Kendrick[40] reports that there are broadly five types of arrangements:

- *The member directed mini-agency* – In this arrangement a group of individuals and/or families decide to establish an agency that will provide support to them. This may be done under a number of different legal structures such as a company, incorporated association or co-operative (section 4.4).

- *Incorporated 'one-off' individual service arrangements* - i.e. Microboards[TM] which are established for one individual and coordinate the support arrangements. Microboards[TM] operate in Australia (section 4.4).

- *Unincorporated 'one-off' individual service arrangements* - In Australia this includes many of the current self-purchasing and direct employment arrangements

- *Agency hosted unincorporated individual support arrangements* – This is where an individual uses a host agency (who will be a formal entity) to manage some, or all, of their Package, pay invoices, and employ and manage the individual's support workers.

- *Agency hosted unincorporated collectively governed individual supported living arrangements* - This is where a group of individuals living together or nearby each other chose to collectively use one host agency (a formal entity). The host agency manages some or all of their Packages and manages the employment arrangements of support workers for each individual. This may or may not involve the pooling of support by group members.

4.3   How are shared living arrangements governed?

Almost all shared living arrangements (for example, student accommodation, housemates sharing a unit or house, families, etc.), even seemingly chaotic households, have some form of governance or decision making structure. Some governance arrangements appear to evolve naturally and others are consciously adopted.

For example, some families or housemates regularly hold meetings and use this as a decision making forum; others appear to make decisions *'on the fly'*, but in both examples, household members are able to identify who makes the final decisions and how decisions are made. In some households there may be a consistent approach about who makes decisions and how they are made. Regardless of how the decision is made, it is likely that the decision will be different to what other similar groups may make (for example, family decisions about how much junk food or screen time is acceptable for their children).

Conflicts regularly occur between individuals living together whether they are students, family members, or members of body corporates, and will occur when people with disability choose to live together.

In shared accommodation and support arrangements governance can broadly be undertaken by three groups:

- *Formal groups* (legal entities), such as:
    - The board of directors of a housing co-operative
    - The committee of management of an incorporated association
    - A Microboard[TM][ii]

- *Formal groups* - these groups have elected members and operate to a formalised structure but are not legal entities in their own right such as:

[ii] A Microboard[TM] will be explained in further detail further in this review. It is important to note that the term Microboard[TM] is trademarked product and the term can only be used when describing this specific product.

- ▪ Residents committees in shared supported accommodation (provided via government or the community sector)
  - ▪ House committees in residential colleges at tertiary institutions
- *Informal groups* - such as governance arrangements in families and share houses.

4.4 Formal groups - governance options

Some groups have the authority to make decisions and others have an advisory or a liaison function. Incorporated associations and co-operatives have the authority to make decisions, while residents' committees in retirement villages and residential park liaison committees in residential parks do not. The level of decision making by residents committees in shared supported accommodation varies from one organisation to another and sometimes, in the case of organisations providing support in a number of houses, from one house to another.

Different governance arrangements apply to different types of corporate entities. While specific governance requirements vary from one type of entity to another, there are some features and requirements that are common to all corporate entities. Groups that are entities:

- Provide protection to members in legal transactions. For example, an entity that enters into a contract may sue or be sued.
- May enter into and enforce contracts, including employment contracts.
- May acquire and deal with goods and property.
- Operate under specific laws and regulations.
- Are required to have some form of constitution, rules and/ or bylaws.
- Must follow specific governance procedures including:
  - ▪ Having a prescribed governance structure such as a committee of management or a board of directors;
  - ▪ Conducting certain meetings, such as annual general meetings;
  - ▪ Certain governance procedures, including procedures in relation to the conduct of meetings, the requirement to keep and audit financial records, voting on issues and resolutions at meetings, and the election of office bearers or directors.

4.4.1 Types of legal entities that can be established by formal groups

There are a number of entities that can be established for the purposes of governing accommodation and/or shared support arrangements.

These entities include:

- Co-operatives
- Incorporated associations

- Microboard™
- Company

Deciding on the type of entity that will enable a group to achieve its objectives is an important decision. The NSW Fair Trading website notes:

'In deciding what structure to choose, you should consider such factors as taxation, type and size of business, finance requirements and establishment costs. Your final decision should only be made after talking to your accountant or solicitor.'[41]

Entities may be established for an individual or a group.

As noted in section 2.5 some types of entities have not been examined in detail. The entities that were not examined are:

- Sole trader
- Partnership
- Trust structures

There are also a range of options for day-to-day operations and support arrangements. A group or individual may operate:

- Without contracted operating arrangements and without a legal entity
- With contracted operating arrangements but without a legal entity
- With contracted operating arrangements and with a legal entity

4.4.1.1 Co-operatives

A co-operative is a member owned business. Co-operatives are different from other forms of incorporation because of their member ownership, democratic structure and the use of funds for mutual, rather than individual, benefit. The establishment and operation of co-operatives is governed by the new national co-operatives legislation, the *Co-Operatives National Law Application Act 2013*. This law was adopted in New South Wales in March 2014.[42, 43]

Co-operatives operate under a set of principles, which are detailed at www.fairtrading.nsw.gov.au and in summary are:

- Voluntary and open membership
- Democratic member control
- Member economic participation
- Autonomy and independence
- Education, training and information (for members)
- Co-operation among co-operatives
- Concern for community.[44]

As they are member-owned, co-operatives allow for a more democratic style of work, the pooling of resources to be more cost effective, and the sharing of skills. Co-operatives supply goods and services to their members or to the general public in areas such as retailing, manufacturing, printing and agriculture. A co-operative must have five or more members.

Co-operatives require specific tasks to be done (such as holding an annual meeting) and require specific documents to be kept (such as financial records). These tasks take time. Directors may be paid for the tasks they do as a director of a co-operative, or act as a volunteer. A manager can be employed to run a co-operative.

The rules of a co-operative set out how decisions are made. This includes how many members need to agree on a decision in order for that decision to apply to all members. A set of model rules is available from www.fairtrading.nsw.gov.au.[45, 46] Co-operatives have rules about active membership. Specialist advice may be required to establish a co-operative where the ways in which members are able to be active may vary significantly from one member to the next.

4.4.1.2 Incorporated associations

The *Associations Incorporation Act 2009* governs how incorporated associations start, how they are run and how they may finish.[47] Incorporated associations have a constitution and can set by-laws. A model constitution is available from www.fairtrading.nsw.gov.au. This forms the rules under which the incorporated association operates. The model constitution may be amended by the incorporated association. For example, Part 2 of the model constitution deals with membership.

However, the model constitution does not consider whether:

- Only the individual entering into a pooled support arrangement may be a member of the association

- The family members and other supporters of the individual may also be members of the association

- Different categories of membership are appropriate, such as associate membership or limited membership.

Specialist advice may be required to identify how categories of membership, such as associate membership or limited membership, may be structured to promote participation, as fully as possible, in the administration of the association by those accessing pooled support arrangements.

Incorporated associations are run by a committee of management. The committee of management includes a president, vice president, treasurer and secretary as well as general committee members. Incorporated associations must conduct general meetings and committee meetings within the rules of the association, maintain records of meetings and decisions, as well as keep financial records. The model constitution does not articulate how governance processes, such as the conduct of meetings or voting on issues, can promote the participation of those accessing pooled support arrangements. These matters may be able to be described in operating principles, policies and procedures.

Incorporated associations require specific tasks to be done (such as holding an annual meeting) and require specific documents to be kept (such as financial records). These tasks take time and are usually done by members on a voluntary basis.

Incorporated associations can be an effective way for people who have a common interest or aim to work together even when they might have different ideas about how best to achieve these aims.

The constitution and rules of an association set out how decisions are made. This includes how many members need to agree on a decision for that decision to be applied to all members.

4.4.1.3 Microboard™

A Microboard™ is a licensed product. To call itself a Microboard™ an organisation must be established and operate under the principles set out by Vela Canada - www.velacanada.org/. In Canada this type of organisation is a not-for-profit society. The equivalent in Australia is an incorporated association. In Australia Microboards™ are licensed through a Perth based organisation (youniverse, www.youniverse.org.au/) that supports the establishment of Microboards™.[48]

A Microboard™ is different to other types of incorporated association in that Microboards™ are established to support one individual. Most incorporated associations are established to serve the needs of a group of members. In addition, they often have broader goals for non-members. For example, a sporting club typically operates to provide facilities and benefits to members and to promote involvement in the sport by non-members. An incorporated association of individuals in a pooled support arrangement may also have as one of its purposes to increase engagement with the local community.

Microboards™ were developed in Canada and are used by individuals with a range of living arrangements, living alone, living with friends or family and living in shared supported accommodation. Because their specific purpose is to support an individual, Microboards™ do not usually manage arrangements where support is pooled by a group of individuals.

4.4.1.4 Company

A private company is a more complex business structure than an incorporated association or a co-operative. A company is formed by one or more people who wish to have a business that is a separate legal entity to themselves.

Private companies are regulated under the *Corporations Act 2001*. This law sets out substantial obligations for company directors. Establishment and ongoing administrative costs associated with corporations' law compliance can be high. This is why the structure is generally considered to be better suited to medium to large businesses.

In Victoria people using individualised funding to directly employ support workers are not able to use a business structure (such as a proprietary limited company) to directly employ staff. This is because the Australian Taxation Office has ruled that

'Individual Support package funding will be treated as income for the business and attract tax which will reduce the amount of funding available to purchase supports.' (p.5)[41]

4.4.2   Informal arrangements and circles of support/support networks

Informal arrangements refer to any accommodation or support arrangement that is not governed by a formal or legal structure (as described above). These can include families, share houses and circles of support. In some circumstances, this could also mean individuals with Packages living together.

A circle of support is a group of people including family, friends and others in the community who form a network around the individual. Typically, the group meets regularly with the purpose of ensuring that the individual is leading a full life. They are often involved in planning and review processes.

Appendix 2 (Key elements of entities) provides a summary of the differences between governance arrangements for the various corporate structures that may be able to meet the aims and objectives of people living together and intending to share part of their Packages.

4.5   What are the benefits, risks or limitations of these arrangements?

Regardless of whether a co-operative, an incorporated association or a series of Microboards™ is established, there are some common benefits, risks and limitations including:

- Providing a legal status which affords some protections against, or in the event of litigation.

- Clear articulation of common purpose (set out in the entity's constitution or rules).

- Clear articulation of how the common purpose will be achieved. This may include adopting operating principles to act as a reference point for making decisions and developing policies and procedures.

- Prescribed governance structure, such as a committee of management, a constitution and by-laws (rules).

Co-operatives and incorporated associations are established to service the needs of members. For family members who hold executive functions in such an entity, making the transition from being an advocate for an individual to managing an entity to achieve a common purpose will be challenging. There will be times when the option that best serves the group may not be the option that best provides the most benefit to an individual resident. Having a clear purpose, principles and governance structures can enable disagreements to be managed in a way that reduces the risk of formal disputes.

The establishment of an entity to manage the pooling of support may result in an increased focus on processes and procedures. Skilled management of decision making and administration is required to avoid a house feeling more formal and less

homelike than was envisaged. Maximising residents' participation in all aspects of governance may act to avoid an *'institutional feel'* and is consistent with the UN Convention on the Rights of Persons with Disability.[49]

Much of the work in managing these entities is done on a voluntary basis. This takes time and in some roles, particularly that of treasurer, specific skills are required. The workload of administering the entity may not be evenly distributed across the membership in a given year or from one year to the next. Without skilful management of group dynamics, the uneven distribution of administrative tasks can become a source of conflict.

Microboards[TM] warrant specific mention as they are a licensed product with a specific purpose and defined principles. To call itself a Microboard[TM] an entity must adopt these principles. Of particular note is the fact that Microboards[TM] have a specific focus on supporting and advocating for an individual. This type of structure would appear to be at odds with the pooling of support by a group of residents. Establishing a series of Microboards[TM] would also create a higher administrative burden on families. For example, each Microboard[TM] would require a treasurer and would need to keep its own financial records. In a co-operative or an incorporated association this role can be undertaken by one individual for the whole group.

Informal arrangements can offer people a range of benefits including more flexibility, and the capacity to innovate and make decisions *'as required'*, rather than a set of rules about the who, what, when, how and why of these types of arrangements.

It should be noted however, that informal arrangements require extra care in a number areas to ensure that *everyone* involved in the arrangement has equal (or as much as they wish) involvement in decision making and that a dominant few do not override the needs of all others. Rules about how decisions are made and how disputes are resolved are still essential in informal arrangements. Where more formal decisions need to be made and actions taken (for example, the employment of staff or the management of shared funds), the lack of a formalised structure may mean that these things are not possible, and may provide no legal protection in the case of an adverse event.

## 4.6   How are disagreements or breakdowns in these arrangements managed?

The Fair Trading NSW website provides information about managing disagreements in community organisations. Incorporated associations must include a dispute resolution process in their constitution.[50] In an incorporated association, the committee of management is responsible for the management of disputes between members and for the management of disputes between members and the association. Dispute resolution procedures for co-operatives are detailed in the *Co-operatives National Regulations* and in the rules of the co-operative once it is established.[53] These regulations include requirements to meet to discuss the disagreement within 14 days and to use mediation where a disagreement cannot be resolved through discussion.

For both types of community groups, a hierarchy of dispute resolution activities is used. Where a disagreement cannot be resolved through discussion between the

parties, alternative dispute resolution procedures are used. These include negotiation, mediation and arbitration. For example, in one individualised accommodation service in Queensland, the board annually appoints an independent mediator whose role is to resolve any issues that may arise between individuals, families, or the agency providing support services.

Only disagreements that cannot be resolved though discussion or alternative dispute resolution processes are taken to litigation. Figure 2-1 illustrates this dispute resolution hierarchy.

Figure 4-1: Dispute resolution hierarchy
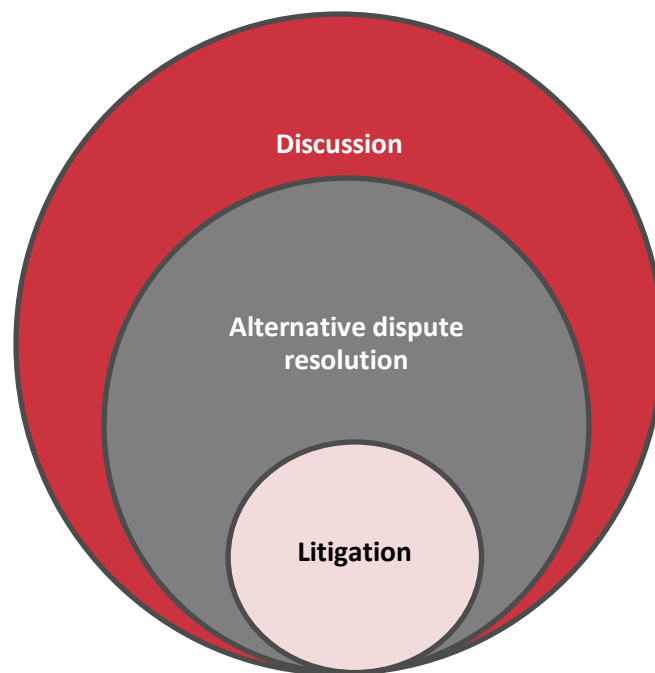
4.6.1 Decision making processes

Appendix 3 (High level decisions) describes some of the decisions that are needed when governing an arrangement, such as a shared living and resource pooling arrangement. Consideration should also be given to *who makes the decision* and *who is responsible for enacting* that decision.

4.6.2 Dispute management processes

Disputes can often arise where not everyone has the same understanding of the purpose and function of the group, or has different expectations of what they will receive or how things will operate.

One way to minimise this scenario, is to ensure that sufficient time is spent in the set up phase to openly discuss each other's perspectives about their expectations and vision and the level of participation they wish in the governance and support arrangements. It is also important to discuss a range of scenarios that could occur and to seek each person's input as to how these issues could be resolved.

Human nature is such that at times disputes occur in any group, including in shared living arrangements. For example, in the Rougemount Cooperative, there were disagreements among members about whether it was reasonable to share support workers. This was managed by referring to the agreed values and principles. As a result, the group decided that sharing support workers was not aligned with their values and principles and sharing of support workers does not occur.[32]

4.7   Examples

Some examples of governance arrangements in shared living arrangements for people with disability are presented in Appendix 4 (Examples of governance arrangements).

4.8   Key elements of good governance in shared living and resource pooling arrangements

Dowson[51] recommends the following elements form the basis of good governance arrangements that are developed for shared living and resource pooling arrangements.

Good governance will:

1. Sustain the legal and financial arrangements required to protect the security of the persons with disability.

   This is likely to involve:

   - The involvement of people, in advisory roles, who can provide expertise required to perform effective governance, for example in law, finance, health and safety, housing, etc.

   - The creation and use of formal procedures (Annual General Meetings, record-keeping, etc.) that are sufficient to meet legal requirements.

   - Adequate reserves being set aside to allow for vacancies, unforeseen expenses, etc.

2. Actively promote a focus on the preferences and choices of each individual, particularly where the focus might be undermined by the compromises required by group living.

   This is likely to involve:

   - Support and respect for the arrangements, such as circles of support and advocacy, designed to promoted the views and needs of the individual in both informal and formal governance processes.

   - Provision for participation, with real influence in decision making, by residents in the recruitment of staff, especially staff who will be providing direct support.

   - Person-centred planning and review methods for each individual that are not dominated by people who operate or have a vested interest in the operation of

Good governance will:

the housing arrangement.

- A person-centred organisational culture.

- Ensuring that staff are trained in person-centred practice.

3. Uphold the rights of each individual, particular where group living, and/or the association of housing and support, might threaten those rights.

This is likely to involve:

- Clear, plain language agreements setting out the terms on which housing and support will be delivered, including the individual's rights to terminate and or change the housing or services received.

- Formal and informal opportunities for individuals to be directly involved in, and to contribute to, decision making, with those opportunities being provided in ways that are accessible, convenient, welcoming and supportive of the individual's contribution.

- Additional provision for each individual, with an advocate if they wish, acting with them or on their behalf, to make direct representation to a higher level of governance where they have a concern or complaint.

- Clear arrangements for filling vacancies which enable both existing residents/tenants and potential new residents to freely choose whether the potential resident will be accepted and will choose to move in.

- Robust financial arrangements, so that vacancies do not have to be filled hastily in order to avoid financial difficulties.

4. Promote the social inclusion of each person in their community, particularly where group living and/or clustered housing arrangements might present obstacles to inclusion.

This is likely to involve:

- Ensuring that any communication with the local community – including the visual messages communicated by the housing itself and immediate surroundings – promotes a positive, socially valued view of the residents.

- Encouraging the use of community resources rather than unnecessarily employing specialist workers or bringing services on site (for example, going out to hairdressers, use of local food shops rather than bulk purchases, etc.).

4.9   Summary

There are many governance arrangements and entities that can be used. Ultimately each group will need to decide which will suit them best, taking into account the level of control, accountability and energy they have and the level of risk they are prepared to carry. The good governance elements recommended by Dowson should create the basis for these arrangements.

5 Governance Framework

5.1 Introduction

Governance refers to the decision making structures and processes that support the establishment and maintenance of the security of the shared living and resource pooling arrangements.

Choosing the right governance model, and establishing a solid framework for governance of a group or organisation, will be a key factor to success and long- term sustainability.

However, there is no perfect governance arrangement - they all have their strengths and weaknesses.[52] Some caution that *'All governance models are subject to failure.'* (p.3)[52] Reasons given for their failure include market failure, parties failing to agree on, or achieve the objectives and failing to communicate, or, in the case of disability services, the funding allocated being insufficient to meet the individual's support needs.[52]

The 'right' governance model and framework will vary depending on the needs of the group or organisation, and the types of 'issues' that will require governance. Appendix 5 (Examples of individualised support in the housing of the person's choice) shows some international and Australian examples of the governance and support arrangements in individualised supports provided in the housing of the person's choice.

It is also important that the model and operations are in line with:

- The key principles and guidelines outlined in Chapter 3
- Their legal and regulatory obligations
- Best practice and are evidence-based (where evidence exists)
- Relevant disability standards and policies.

While there is little research on how to choose and establish the right governance arrangement for a particular group establishing new housing and support options, Appendix 5 presents a range of decisions that will need to be made depending on what living arrangement is chosen, and as such, forms an overall governance framework. It should be noted however, that this is not, nor it is intended to be, an exhaustive description of all the living and support arrangements possible. The focus has been placed on the most likely arrangements, and those in particular that create opportunities for the pooling of part of an individual's Package.

5.2 What are the key elements of the governance framework?

Based on the Governance Framework presented in Appendix 6, this section provides further detail about each of the key elements and success factors related to

governance, operations, and day-to-day living arrangements identified in the literature.

5.2.1 Living arrangements

Within individualised funding the individual chooses which living arrangement will best suit their needs and preferences. As a result, people may choose to live in a variety of arrangements. Individuals who chose to live alone may do so because they like the independence and freedom it may offer, but shared living may provide greater opportunities for *'real people connecting, supporting and sharing their lives'* (p.4).[18]

Broadly these living arrangements may include living with family, or living alone, or in shared living arrangements with unrelated people. These shared living arrangements include but are not limited to:

- Living with, or in close proximity to two or three other people with disability (for example, duplex, villa units)

- Living with a person without disability who provides some support

- Living with a host family that provides some support

- Living with three or more people with disability in the same house (often termed group homes) or block in a cluster arrangement

- Living in a neighbourhood or locale where others with disability live (such as in KeyRing Models).

5.2.1.1 Living with their family or alone

Most Australians with disability live with their families. The benefits of this option include:

- living with people who know you well,

- ready access to support by family members,

- involvement in family activities,

- cost effectiveness (not paying open-market rent).

However, the ongoing caregiving demands can have a negative effect on family members, and the protective behaviours of some families may limit the person's opportunities. Many family members and people with disability report feeling trapped into this arrangement long into the person's adulthood, due the lack of adequate support funding. Some people may attend day services and/or receive funding for community access or respite, but find this is insufficient for covering their support costs to move out of the family home.

Like their siblings, many young adults and adults would like to live alone.[17, 53]

This report will not discuss arrangements for people with disability living with family or living on their own (without shared support), as these do not require a governance arrangement and typically do not involve two or more people sharing supports.

5.2.2   Shared living arrangements

Within the disability sector there are a range of shared living arrangements and definitions about what constitutes shared living. In the UK shared living is described as encompassing the following set of principles:

- I choose who I live with

- I choose where I live

- I have my own home

- I choose how I am supported

- I choose who supports me

- I get good support

- I choose my friends and relationships

- I choose to be healthy and safe

- I choose to take part in my community

- I have the same rights and responsibilities as other citizens

- I get help to make changes in my life. (p.7)[54]

However, the definition developed in Western Australia (WA) expands this to include sharing one's life. To illustrate, shared living is defined as offering *'an individualised and tailored approach to match and support people's differences and uniqueness, offering people the opportunity to share their lives not just their accommodation.'* (p.6)[18] Some key principles have been developed for the WA shared living arrangements, these include:

- Independent living

- Self-determination

- Belonging and connecting

- Flexibility

- Choice

- Trust.[18]

5.2.2.1 Living with two or three other people with disability

This option is for those who wish to live with friends and may include living in a house or unit. Each person would have their own bedroom (some may have en-suites) and share the living areas. This option allows them to share their costs (including support costs).

5.2.2.2 Living with a person without disability who provides some support

This arrangement is sometimes referred to as co-tenancy, Lead Tenant or Homeshare, or in New Zealand if is referred to as Contract Board.[55, 56] It is used in a number of settings including aged care and disability. In this option, the person may

have a two or three bedroom unit and advertise for a person to share with them, or find someone to share with and they both locate a house/unit to live in. In some situations the person may move into the supporter's home.[18] Some services, such as Wesley Mission Victoria, provide a matching service for potential home-sharers and volunteers.[56]

In lieu of all, or part of their rent, or by receiving payment, the co-tenant provides some informal support. As they are living in the same home they are typically available overnight and for any unexpected events that occur. Another benefit of this arrangement is that it can extend the person's social connections and participation. There are some reports that it also creates opportunities for reciprocity.[18, 57] For example, if the co-tenant is an overseas student, the person with a disability may assist them with their English.

The challenges include:

- Finding people who are willing to enter this type of arrangement,[38] although some models have been operating successfully in Australia, with some home-share arrangements lasting over 5-7 years.[57]

- Filling the support gap (if one exists) between the co-tenant leaving and a new co-tenant being found.

- Ensuring that the co-tenant delivers the support.

Not all of these arrangements are full-time. There are reports of some arrangements being part-time or occasional, for example the person may go and live with the co-tenant on weekends (or vice versa).

5.2.2.3 Living with a host family or person who provides some support

In this arrangement the person lives in the host family's or supporter's house and pays them rent. In some international schemes, the host family is remunerated for providing the person with 24/7 support and is also expected to arrange the person's paid supports. Some host families will support two people, which may create an opportunity for the two people to pool some of their funds and/or supports.

5.2.2.4 Living with four or more people with disability in the same house (often termed group homes) or in a cluster arrangement

The most dominant shared accommodation and support in Australia is the group home model. In the traditional model, the property owner is typically the government or a community service organisation, which also provides the support. Each person has their own bedroom but may share bathrooms and living areas.

Issues of incompatibility, inflexibility, lack of individualised supports and poorer outcomes and an increase in challenging behaviour are frequently raised in the literature as occurring in these arrangements.[58, 59]

If this option is being developed for a group of individuals who genuinely wish to live together and all have Packages, then they can have more choice over who provides their supports and how they wish their daily lives to be. It may also offer good value for money, if they choose to pool some or their support funding. However, vigilance

is needed to ensure that it does not revert into the traditional group support model with little or no opportunities for individualised one-to-one support based on one's goals.

5.2.2.5 Living in a neighbourhood or locale where others with disability live (such as in KeyRing Model)

In any community there are likely to be others with disability. Some models have emerged that support individuals living in a geographical locale. For example, the KeyRing model developed in the UK. This is based on around 8-10 people with disability with individualised funding, who live in their own units that are within walking distance (or easy public transport access) of each other. A person (who lives in the same area) is recruited. In some models the coordinator is paid and in others they are a volunteer. The coordinator helps to establish and maintain a mutual support and social network between all the members. Each individual can also purchase supports through their individualised funding. In one example, a co-operative was established to run the arrangement.[38]

5.2.2.6 Living in an intentional community that accommodates people with and without disability

Intentional communities have been established in Canada, UK and Australia by families who wish to create a supportive and 'welcoming community' for their sons and daughters with disability. These include a mix of people with and without disability. These arrangements are not to be confused with cluster or village arrangements developed only for people with disability.

Each of the individuals decides if they wish to live alone or share their unit with another person. The families (and someones) develop an informal network of support for their sons and daughters through recruiting people with the same values to live in the community. All community members are expected to be good neighbours, to assist others and contribute in generating a community spirit.[32, 60]

5.2.3   Tenancy arrangement

Having your own home *'guarantees a place in the community and is part of how people are accepted as equal citizens.'* (p.5)[54]

Security of tenure is an important component of general wellbeing, but is sometimes hard to obtain. Some individuals will seek rental security while others may want to obtain equity in one's own home.

Possible tenancy arrangements include:

- Home ownership
- Private rental
- Social housing
- Co-tenant arrangement
- A room in the house of a host family

- A room in a house with 4 or more bedrooms for people with disability
- A unit (for one or two people with disability) in a cluster setting with other units for people with disability.

5.2.3.1 Home ownership

The level of home ownership among Australians with disability is lower than for non-disabled peers. Various equity arrangements, such as the Mixed Equity Program offered by Housing Choices Australia are available. Commonwealth Special Disability Trusts have been established to assist families to provide security in relation to *'care and accommodation'* for their sons and daughters with disability without affecting the individual's entitlement to social security benefits or attracting gift tax.[61, 62] There is a need for ongoing policy attention in this area to increase the home ownership opportunities for Australians with disability, as it is one of the markers of citizenship and equality.

In this option, the person or their family would be responsible for servicing the mortgage (if applicable).

5.2.3.2 Private rental

It is widely acknowledged that affordability is a major barrier for people living on disability support pensions, to access private rental properties. A shortage of accessible rental housing is also problematic for people with mobility issues.

There are some international models that assist landlords to undertake renovations to create accessible homes. Some also provide support to landlords to offer tenancies to people with a mental illness.[57]

Where a private rental is found, the individual enters into a tenancy contract and is responsible for their rent, etc. In the event of a dispute, the relevant Residential Tenancy Act would apply.

5.2.3.3 Social housing

There are long waiting lists to access social housing in Australia and not all social housing is accessible. Some new options based on partnerships with community housing providers are emerging, and they offer greater opportunities for people with disability, as many of them allocate a set number of units for people with disability.

Like private rental arrangements, the individual is responsible for the rent and utility costs.

5.2.3.4 Co-tenant arrangement

In this arrangement the person/s with disability pay/s the full or partial rent or if they own the home, they do not charge the co-tenant rent.

The parties would need to decide on the tenancy arrangements and if it proved to be unsatisfactory to either party, then what action would be taken.

5.2.3.5 A room in the house of a host family

In this arrangement the individual pays rent to the family. The family would either be the landowner, or if it was a private rental or social housing, they would be responsible for the tenancy.

5.2.3.6 A room in a house with 4 or more bedrooms for people with disability

Typically in these settings (often referred to as group homes) residents pay rent and contribute towards household costs (utilities). Some people living in these arrangements do not have access to the Tenancy Act, but are instead covered under state disability legislation. These houses are required to meet specific regulations (for example, fire sprinkler systems, etc.) and are visited (unannounced) in some states under the Community Visitors Program.

In options where a group of people with disability or their family/carers choose to purchase or rent a house, then they would determine the tenancy arrangements. They would also need to discuss with the relevant government departments, their obligations in regard to any regulations they would need to comply with or any exemptions.

5.2.3.7 A unit (for one or two people with disability) in a cluster setting with other units for people with disability

Depending on the arrangement established these units could be:

- Owned by the individual or their family
- Rented by the individual under separate tenancy arrangements
- Rented under a lead tenancy arrangement to the entity - which is then responsible for managing any vacancies, etc.
- Owned or rented by a service provider
- Owned by a community housing provider.

5.2.3.8 Intentional community

The tenancy arrangements in place would depend on how the intentional community was established. The housing may be privately owned, private rental or social/community housing.

5.2.4 Choosing the right entity

As described in Chapter 4, there are a range of entities or arrangements that can be entered into depending on the needs of the person or group.

Depending on which governance arrangement is chosen (particularly for incorporated associations or co-operatives) a range of legal and financial requirements will need to be fulfilled. These requirements include (but are not limited to):

- the establishment of a deed or constitution

- membership

- keeping financial records

- annual general meetings

- sub-committees, etc.

For many of these requirements, decisions will need to be made that best suit the needs of the organisation.

They will also need to discuss and agree on who makes the decisions and how. For example, do some decisions require full endorsement or majority endorsement? Can some members make decisions on behalf of others? And, how they will ensure that the views of all the people with disability will be heard and they are involved in decision making.

5.2.5   Decision making, disputes and risk management

As presented in Chapter 3, a critical element of the governance framework will be an agreement about who will make decisions on the range of areas discussed above. While the 'decision makers' may vary depending on the issue, or the person's skills, abilities and interests, having a documented approach in place about processes means that everyone will be clear about the process, and there will be less risk of disputes arising.

Decision making may be vested in small working groups or sub-committees, paid employees (where there are some), individuals and families, or whole groups (Appendix 4). It is also important that there are clearly defined roles and responsibilities about decision making, and then who enacts the decisions. There is also a need to have a clear dispute resolution process. Finally, it is essential that potential risks (at the entity, support and individual level) are identified and mitigation strategies are discussed and agreed.

5.2.6   Overall management and coordination

Depending on the number of people choosing to live together and the level of participation in day-to-day operations desired by people with disability and their families, it may be useful for some groups to consider appointing a manager or coordinator.

Some similar arrangements have included either full or part-time coordinator. The role differs from one setting to another. For example:

- In the Rougemount community a family coordinator has been appointed. Their key role is writing submissions for funding, working with families and assisting families to appoint support workers. They do not coordinate the support workers, but may provide some training. The family coordinator has intentionally not been provided with office space, as this was deemed to make it feel too formal and the desire is that they are most often meeting with families and individuals in their homes.

- The role of the coordinator at Living Distinctive Lifestyles assists with individual support planning, manages budgets, support worker employment and supervision, assists in developing safeguards and circles of support, and researches housing options.[63]

5.2.7   Package management

Within each jurisdiction and scheme there are various options for how individualised Packages can be managed. NSW includes the option of an intermediary model, where individual funding is paid by ADHC to an intermediary who administers and monitors the Package. The maximum administrative fee that an intermediary can charge to administer the Package is 12% of the cost of supports (this fee is funded in addition to the supports). The intermediary has obligations to report to ADHC on expenditure and purchases.[64]

Under the NDIS, participants (the term used for people who are eligible for the NDIS) can choose to:

- Manage the funds directly or ask a nominee (for example, family member) to manage the funds (via direct payments)

- Use an intermediary to administer the funds

- Have the National Disability Insurance Agency manage the funds

- Use a combination of these arrangements.

There are overseas reports of some family-governed accommodation options which have encountered fiscal issues due to insufficient funding levels for the supports needed by the individuals, difficulties enlisting co-tenants who would provide some support in lieu of rent, or unanticipated property damage.[36, 38]

Each individual will have their own support plan and funding allocation and should to the greatest extent possible, receive tailored supports to meet their personal goals. Individuals would have control over their own Package so they can purchase individual supports and services.

5.2.8   Support coordination

Options for coordinating the day-to-day supports within the shared arrangement will depend on the amount of control the individual, family or entity wish to have. The options for support coordination include:

- The individual or their family/carer

- A circle of support

- The service provider (if appointed)

- The entity

- The house manager or coordinator

- A team of directly employed support workers

- The intermediary

- A combination of the above.

5.2.9   Support provision

If some supports are to be shared, agreement will be needed about the support model. This will include the principles, values and the desired outcomes.

Each group will need to decide on how much (if any) of the support will be shared and how much will be individually determined. They will also need to discuss if they have any preferences about support providers and how the support is to be provided. For example, Active Support and Positive Behavioural Support have been shown to be effective.[15, 65, 66]

Decisions will also need to be made about the level of oversight or control individuals and families wish to have over the support arrangements, as well as:

- Will they use a disability service provider?

- Will they directly employ a team of support workers? If so, will each individual or their family become the employer, or will the entity, or will they appoint a third party to manage staff pay and entitlements, etc.?

- Who will be responsible for developing policies and procedures, staff training, supervision, etc.?

A tool, such as the one developed by Inclusion Melbourne will be useful when interviewing potential support providers and making decision about who to appoint.[67] It is also available in an Easy English format.[68]

Decisions will need to be made about how to best use individual support funds and what other support options (family, neighbours, community, smart technology, equipment, assistance dogs, etc.) could be considered. For example, smart technologies have been reported to reduce the need for human support by 23% without adverse effects of the residents quality of life.[69] However, in regard to surveillance technology there are tensions between what constitutes safety versus privacy, freedom or autonomy.[70]

5.2.9.1 Use of informal and community supports

Due to the evidence that people with disability living in group homes often have few friends or community connections,[58] a number of papers highlight the need for new support models to ensure connections are made in the local neighbourhood and community.[32, 38] Many have harnessed strong informal supports from a range of sources including family, friends, neighbours, community members, co-tenants (such as in time share) or others with disability (such as in KeyRing models). The effective use of informal supports can achieve a range of outcomes - it creates greater opportunities for the individual, it creates a sense of community and belonging, it can also keep the individual safe, and increase their self-esteem.[36]

5.2.10 Household costs

Decisions will be needed as to how day to day household costs will be managed. These include:

- Rent or mortgage
- Utilities
- Food
- Cleaning products and other household items
- Pet cost (optional).

5.2.10.1 Rent

The property owner (if the owner is the person with disability or their family) will set the requirements for bonds, notice to exit the property, rent and payment arrangements. Rent is each individual's responsibility and cannot be paid from the individual's Package.

5.2.10.2 Utilities

The utilities could be arranged in the following ways:

- Each person has separate arrangements for water, electricity gas, internet, phone and pays their own costs.
- Some element are shared (for example, electricity, water, gas) when it is a house or if there are separate communal areas, but each individual separately pays their own phone bills, internet bills, etc.
- All the bills are divided equally among the individuals.

Issues could arise when people's need for utilities varies. For example, one person has a need for the room temperature to be kept stable (due to their health or disability) or some want pay television but others do not, or some constantly use the Internet, but others do not use it at all. There may be reluctance to share the additional costs if there are significant differences in their usage.

5.2.11 Food and meals

A range of options exist when two or more people share their living arrangement in regard to food and meals. These could include:

- All parties contributing to the grocery bill
- Cooking the meals together
- Each individual purchases their own food, prepares their own meals
- If communal meals occur, each person contributes equally to the food costs for the communal meal, but otherwise they purchase their own food
- Two people decide to share the food costs and cook together

- Each person (or family) identifies a night to cook for the group and pays for the ingredients for this meal. Outside of these shared dinners each individual purchases their own food.

Each individual will need to express their preference in regard to how they wish to manage food arrangements and then an agreement will need to be reached.

5.2.11.1   Pets

The issue of pets will need to be discussed. Some groups may decide to have a shared pet with each person contributing to their care and costs. Others may decide that pet ownership is not for them or will not be possible (for example, in the event someone has an allergy, fear of animals, etc.). Some groups may decide that pet ownership is an individual decision.

5.2.12   Daily life and participation

One of the guiding principles of individual funding is that it *"should help to improve the person's social and economic inclusion".*[iii]

5.2.12.1   Daily life and routines

It is essential that each individual decides on their daily life and routines. This includes what time to get up, eat, shower, etc. and how they spend the day.

They should each participate to the greatest extent possible in daily activities. Active support models for people with developmental disability requires support workers to proactively engage the individual in a range of daily activities and for workers to refrain from *'doing for'* but instead to *'do with.'* This includes shopping, meal preparation, cleaning, gardening, etc.

The support arrangements should also provide some flexibility, so that people can go out of an evening, away for a weekend, or on holidays if they wish.

5.2.12.2   Participation

Finding meaning in life and participation in valued roles is essential for all people. Any support arrangement should promote community inclusion and participation in activities of the person's choosing. However, people should choose the level of community participation that they wish.

Many people with disability report being lonely and not having a friend. Creating ways to assist people to develop genuine friendships will be valuable. Further, there is increased focus on education, volunteering and work under the NDIS.

Best practice indicates that engagement in community activities should be based on the person's interests and aspirations. This type of support is likely to be individualised rather than shared - unless a group with similar interests (for example,

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[iii] Individual Funding Handbook, pg. 9

they all support the same football team and like to attend the matches) wish to pool their support for this activity. There is also an important role for informal supports and community clubs in supporting people to be part of their local community. This has the added benefit of assisting people to feel safe in their community.[61]

6 Conclusion

People with disability in NSW are being provided individualised funding with greater choice to decide where they wish to live, with whom, and how. Consequently new options are being developed by individuals and their families.

This literature review has identified some key principles, guidelines and elements related to developing formal arrangements when individuals and families choose to share their accommodation and/or some supports, and to enter into governance arrangements.

The *Individualised Funding Governance: Resource Literature Review* provides information to help individuals make an informed decision about how they might pool a part of their Packages, supports and household costs, if they choose to do so.

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