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Introduction

This Person-Centred Guide has been developed in conjunction with the Human Rights Guide for the South Australian Disability Sector. It recognises the importance of people living with disability realising and claiming their rights. For all citizens, a key part of exercising their rights is the capacity to make their own decisions and fulfil their dreams. For people with disability this will be achieved through setting goals for themselves through authentic person-centred planning and support in all facets of their lives. It will require the commitment of Boards, managers and all staff to ensure that we really put people with disability in charge of their own lives.

Background

DCSI is committed to best practice and service improvement not only in the services it provides but also in those organisations it currently funds. DCSI also acknowledges the evolution of service models, which has led to a strong focus on people’s rights, increased opportunities and personalised responses for individuals and the strong leadership of some organisations in making those changes.

The United Nations has played a significant role in raising awareness about the rights of people living with disability through the Declaration of Rights of Disabled Persons (1974) and the International Year of Disabled Persons (1981). However, it was not until the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) that a genuine recognition of the human rights of people living with disability was clearly articulated. Australia, along with many other nations, has ratified the Convention, and this imposes obligations on all service providers to respect, protect and fulfil the rights of all people living with disability.

Understanding Person-Centredness

“….for organisations to move away from systems-driven strategies to supports that are person centred, shifts in the organisation’s strategic direction need to happen. ...culture, leadership, organisational structure and the design of supports to individuals must align with the values of person-centred approaches and thinking.”

Cornell University

Person-centredness helps uphold people’s rights and see their goals and aspirations realised. Person-centred thinking, practice and integration across the organisation are integral to full realisation of human rights.

Authentic person-centred practice supports the creation of meaningful connections for people living with disability outside of a ‘service system’. It facilitates people genuinely participating in valued and meaningful activities in everyday life, contributing as members of their community and forming relationships with service providers that are ethical and honourable.

Person-centredness simply means getting to know a person, listening to what and who is important to them and understanding what their wishes and aspirations are. Once this is understood, it is possible to support people in order for their dreams to be realised.
How Person-Centredness Underpins Social Inclusion

Research and evidence show that people living with disability achieve full inclusion and active, valued roles in the community when person-centred planning and support are used. Planning must place greater emphasis on:

- The importance of social contribution
- Intentional facilitation of relationships
- Valued roles
- Challenging negative stereotypes
- Ensuring a base of questioning, reflecting and reviewing.

Services maintain that people living with disability have the right to not only be present in the community, but to belong and fully participate in community life. This is in line with the NDIS outcomes for social and economic participation.

“Person-Centred Planning is not simply a collection of new techniques to replace other forms of planning. It is based on a completely different way of seeing and working with people living with disability which is fundamentally about sharing power and community inclusion.”

Helen Sanderson (Person Centred Planning: Key Features and Approaches, Joseph Rowntree Foundation, 2000)
Authority, Control and Power in a Person-Centred Approach

An essential element of person-centredness and a human rights approach is addressing the issue of power and control. This means shifting the power from professionals, to the person living with disability and their family. It is built on the assumption that no organisation ‘owns’ a person’s life – the person and their family has this ownership.

Moving from a position of ‘power over’ to ‘power with’ will support people and their families to assume the authority and decision-making in their own lives.

Person-Centred Partnerships with People and Families

Partnership implies that all people have equal status in the relationship. Genuine partnership will mean that people living with disability, their families and allies will support them with what they want and we will determine how they will support them to make it happen.

Elements that demonstrate a partnership that is both ethical and fruitful include:

- **Truthful and transparent communication and cooperation:**
  Remaining truthful in words and conduct even though they will not be without fault.

- **Constant communication:**
  The partnership is actively pursued by both parties and people living with disability and families are not excluded from relevant and important information.

- **Commitment to promises:**
  Promises made are promises kept.

- **A focus on the real issues in people’s lives:**
  The priorities or constraints of our services are hurdles to be overcome, but they do not take over the focus of the person’s life.

- **Authentic sharing of power:**
  There is serious commitment to listening to the person living with disability, their family and allies.

- **Acknowledgement of failings and limitations:**
  Both parties assume responsibility for recognising failings and limitations. Partnerships will become possible when we do not view people living with disability as ‘clients’, and where the dominant view is shifted to planning with people while taking into account the cultural and social context of each person.

Tailoring Support to the Person

Person-centred conversations change the focus from ‘this is what we do,’ to ‘what do you want to do and how can we support you to achieve this?’

Individualised funding is one opportunity to move forward in individualising support around the person and respond more flexibly to the person's goals and aspirations.

Another is support staff. People need to receive support from people they select as right for them. This potentially requires a radical change in personnel and recruitment processes for DCSI and the transformation of existing service delivery.
Dealing with Structural Barriers

Organisational structures, policies and practices that respect, protect and fulfil human rights are vital for the success of person-centred approaches and planning.

Approaches used to deal with barriers to embedding person-centredness include:

- **Pace of change:**
  Cultural and structural transformation must be addressed if people living with disability are to experience a different way of thinking about their future. Organisations must give a long-term commitment to support change for each person.

- **Roles of staff:**
  Fundamental in moving towards person-centredness are the roles of paid support staff and a change in the relationship between staff and the people they are paid to support. The focus of the role moves to that of a personal assistant, with more time spent on supporting the person to make connections in the community, develop relationships, and matching people based on interests and the needs of the person being supported.

- **Resistance:**
  Common and repeated themes of ‘we already do this’, ‘we can’t change what we do’, ‘we are not allowed’, ‘there is nothing wrong with what we are doing’, requires creative and intentional focus on managing the cultural change process.

- **Providing everything:**
  Alongside developing partnerships with people living with disability and their families, organisations must form alliances and relationships with the local community to ensure that we are not the sole supporter and provider to people.

**Supported Decision-Making**

Supported decision-making is endorsed by the principles of the UNCRPD, specifically Article 12 that affirms that people living with disability have the right to recognition before the law and that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”. Where people are denied the right to make decisions or some types of decisions, they are potentially being denied their human rights.

Services must provide support for decision-making instead of appointing another person to make decisions for people living with disability.

**General principles:**

- People living with disability must be informed of their human rights and are supported to exercise these rights.
- People living with disability have the right to take their own chances and make their own mistakes.
- People living with disability have the right to have access to appropriate assistance and support that will enable them to maximise their capacity to exercise choice and control, and realise their potential.
People living with disability are empowered to determine their own best interests, including the right to exercise informed choice and take calculated risks.

**Decision-Making when a Person has Capacity**

People need to make many decisions including legal, financial, health and wellbeing, lifestyle and social. Service providers may help to make these decisions. However, we must ensure that the autonomy and independence of the person living with disability is maintained at all times.

For people who do not require support in decision-making, disability service providers must respect and support the individual’s decisions.

For people who require some support in decision-making, we must help them access appropriate support and information to enable the person to make the decision for themselves as far as is practicable. Disability service providers should recognise that a person’s views may be expressed through body language, behaviour and/or through a variety of verbal or non-verbal signs. Augmentative communication aids may be used to assist communication.

When supporting someone in their decision-making there are some important questions to consider:

- Do I fully understand what is important to the person and their communication?
- Am I the best person to support this decision-making?
- Is the information that I have and am giving the person relevant to the decision?
- Am I presenting it in a way that the person can understand?
- Am I giving the information in the right place and time?
- Have I given the person the best chance to make the decision themselves?

Refer to Appendix 2: Supported Decision-Making.

”Because personal autonomy and self-determination are fundamental, there is no debate that it is better for people to make a decision for themselves, rather than have a decision made for them.”

John Brayley (Former Public Advocate, South Australia)

**Decision-Making when a Person is Determined to not have Capacity**

In a situation where a person may not have the capacity to make their own decisions, we must ensure that the person is supported as much as possible to express their views and decisions. This may include working with a person’s family, nominated support and/or legally appointed guardian, where relevant. Supporting a person’s decision-making can be formal and informal.

**Informal decision-making on behalf of a person with disability**

We must ensure all informal decision-making arrangements are recorded and communicated to relevant staff. Decisions can then be pursued through the agreed informal arrangements.
If informal arrangements are not yet in place, or do not apply to the specific situation, the person with disability, along with relevant family, friends or carers, must be involved in the decision-making process.

**Formal decision-making on behalf of a person with disability**

Informal arrangements can be considered insufficient when there is conflict over decisions being made about the person or where the person is at risk of self-neglect or abuse. In this case, an application for Guardianship or Administration Orders can be made to the South Australian Civil and Administrative Tribunal (formally the Guardianship Board).

Formal arrangements should take a rights-based approach and consider the person’s individual wishes as much as possible despite their mental incapacity.

**Recording Decisions**

All decision-making arrangements for a person living with disability, whether formal or informal, must be recorded and maintained. All consent and decision-making arrangements must be reviewed regularly to ensure changes in capacity or process are captured and recorded.

**A Person-Centred Approach to Risk**

Traditional risk assessment processes are recognised as being restrictive and limit the opportunities of people living with disability (Bates and Silberman 2007).

A person-centred approach to risk seeks to focus on people’s right to have the lifestyle that they choose, including the right to make 'bad' decisions.

The approach described here uses person-centred thinking tools to help people and those who support them, think in a positive and productive way about how to ensure that they can achieve the changes they want to see, while managing risk appropriately.

In the person-centred approach to risk, a person living with disability gathers, with their supporters, detailed information and evidence to demonstrate that they have thought deeply about all the issues involved. Decisions are guided by what is important to the person, what is needed to keep them healthy and safe and on what the law says.

**What is risk?**

Risk is a measurable probability that something will happen. In human services, risk is often understood to represent the likelihood of an unforeseen or negative event occurring as the result of a decision or action. A person may be described as a risk to themselves or others.

Differences in power and status affect the extent to which people influence risk decision-making. This can translate into a more intrusive approach to behaviours, real and potential, of the people they support. There is also a tendency to confuse organisational risk (that is, negative consequences for the support service) with personal risk (such as consequences for the person making the decision or performing the ‘risky’ action) and this can also lead to a reluctance among supporters to assess risk in a natural or progressive way.
Traditional risk assessment processes encourage practitioners to look for what is going wrong rather than what is going right, ultimately disempowering people, reducing safeguarding opportunities and restricting rights (Booth and Booth 1998).

Person-centred approaches focus on building an alliance of supporters around the person living with disability to generate new and creative ways forward.

Adopting a person-centred approach to risk will require DCSI to take a positive risk-taking approach whilst ensuring reasonable protection for the person and the community based on minimising harm.

**Essential Criteria for Assessing Risk**

The following essential criteria (Bates and Silberman 2007) provide a framework for assessing risk, using a person-centred and rights-based approach:

- **Involvement of service users, families and allies in risk assessment:**
  Involvement of the person, family and allies is vital in achieving a person-centred approach to risk. Involvement starts at the initial stages of gathering information, problem-solving and brain-storming, to decision-making and managing any risks using relevant tools. 
  This results in ownership, evaluation and learning opportunities for everyone involved.

- **Positive and informed risk taking:**
  This begins with a positive view of the person and learning about what they like to do. This approach balances what is important to that person with what is important for that person. It focuses on finding creative solutions rather than ruling out opportunities.

- **Proportionality:**
  This approach explores the effects of not taking the risk to the person and weighs this against the consequences of taking the risk.

- **Contextualising behaviour:**
  This looks at why the person has decided to behave in this way. It explores people’s history from their perspective and provides a process to best support the person with what has already been learnt.

- **Defensible decision-making:**
  The approach provides a clear documented trail of what has been discussed and any decisions. This could include different perspectives, rationales and legal issues that have affected the risk decision.

- **A learning culture:**
  This approach requires an ongoing commitment to learn from actions and experiences. The tools that support this include a learning log (what’s working/what’s not working) and clearly defined staff roles and responsibilities.
• **Tolerable risks:**
  Tolerable risk looks at creative techniques to mitigate risk and improve quality of life for people living with disability. The aim is to move from a situation in which the person is safe but unhappy, to one in which they can be happier whilst keeping themselves and the community safe. This approach takes a balanced and rational approach to risk.

Refer to Appendix 3: Person-Centred Approach to Risk Flowchart.

> “Every opportunity contains risks – a life without risk is a life without opportunities, often without quality and without change.”
> Helen Sanderson (Person Centred Planning: Key Features and Approaches, Joseph Rowntree Foundation, 2000)

**Conclusion**

Increasingly, legislation, policies and standards are being enacted to respect, protect and fulfil people’s human rights. Human rights underpin the NDIS legislation and are the foundation on which the shift to self-directed approaches is built. The challenge for organisations is to build human rights into the heart and practice of all service provision. A human rights and person-centred approach to service delivery is essential for people living with disability to increase their opportunities for experience and to exercise choice and control in their own lives.

Achieving genuine person-centredness in staff teams, planning and support is crucial in order for people living with disability to enjoy a life that is socially inclusive and provides opportunities to fulfil active and valued roles in their communities.

The Human Rights and Person-Centred Guide for the South Australian Disability Service Sector has been developed to promote greater awareness and understanding of human rights and person-centred practices and inform future service delivery.

The Guide describes how we will support people to lead full lives through a rights-based, person-centred approach.

> “The ups and downs of a respectful relationship will create a new knowledge of capacities and interests and identify new possibilities to try.”
> John O’Brien (The Centre for Welfare Reform, UK)
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J Brayley, *Supported Decision Making in Australia* – Presentation Notes, Office of the Public Advocate South Australia, 2009

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Yorkshire and Humber Joint Investment Partnership & Yorkshire and Humber Valuing People Support Team, *Person Centred Approaches 2010 and Beyond: A Toolkit to review Person Centred Planning and Approaches*, United Kingdom: Paradigm, 2011


H Sanderson, *Person Centred Planning: Key Features and Approaches*, Joseph Rowntree Foundation, 2000


Office of the Public Advocate, *Supported Decision Making*, OPA website
Appendix 1: Statement of Intent

Do With Not For Disability Services

“The South Australian Government will ensure our disability support system offers people with disability and their families the control and choice that they want. We are committed to providing a better life for adults and children with disabilities and their families.”

The Hon Tony Piccolo MP, Minister for Disabilities

The Department for Communities and Social Inclusion supports the United Nations Convention on the Rights of Persons with Disabilities. The department is committed to safeguarding, promoting and fulfilling the human rights of people with disability by adopting a person centred approach to the provision of services and through active participation and decision making by people with disability.

The department will uphold attitudes and values that honour a person’s unique individuality and perspective and promote their full inclusion. We are focused on the person’s aspirations and wishes. The person and their family are at the centre of all we do. They are supported to make their own choices.

The United Nations Convention on the Rights of Persons with Disabilities includes:

“The need to promote, protect and fulfil the human rights of all persons with disabilities.”

“The importance to persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices, and considering that persons with disabilities should have the opportunity to be actively involved in decision making processes about policies and programs, including those directly concerning them.”

Active Support assists people with disability to have meaningful and active roles in their lives and communities.

In working with people, not for people, we will champion:

- **Respect for people and families**
  by listening and responding to their wishes.

- **Family centred practices**
  by recognising and supporting families in their caring role.

- **Choice and control**
  by providing information, resources and services to support people to make their own decisions.

- **Inclusion**
  by working with and promoting the rights of people with disability to access and participate in their community.

We actively promote a community that includes and values all people, offering meaningful choice and participation.

Joslene Mazel
Chief Executive
Department for Communities and Social Inclusion
June 2013

Communities for all: opportunities for everyone
Appendix 2: Supported Decision-Making

A Stepped Approach to Supported and Substituted Decision-Making (adapted from the South Australian Office of the Public Advocate’s Stepped Approach to Supported and Substituted Decision-Making Model, August 2010). This model recognises that there is not just one form of supported decision-making within the total spectrum.

**Autonomous Decision-Making**

No assistance or support required but assistance for support and advice may be sought by an individual.

**Assisted Decision-Making**

In coming to an autonomous decision, if a person requires assistance with collecting information, explanation of alternatives or communication, they should be given the option of drawing up a decision-making profile to assist and maximise power and control.

**Supported Decision-Making Agreement**

(non-statutory model)

An agreement indicates a person’s wish to receive support. This may include agreement on when informal substitute decisions take place. A person can end this agreement at anytime. A person is not required to use the agreement. A person is given the option of drawing up a decision-making agreement and profile to assist and maximise power and control.

**Substitute Statutory Decision-Making Agreements**

Appointment by the Guardianship Board of South Australia – options could include a private or public guardian being appointed.

Increasing Care and Protection and Increasing Intervention by the State.
Appendix 3: Person-Centred Approach to Risk

A person-centred approach to risk uses questions around a framework of purpose, people, process and progress – it is important that at the beginning of the process we think seriously about what it is we are trying to achieve. Our thinking about how the process can be used to enable the person to have choice and control in their life, and to be a citizen in the community, will influence who the people are that are called to participate in the process.