Working in Person Centred Ways:

A Resource Book for NSW Advocacy and Information Services

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Ageing, Disability & Home Care

The Authors

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Contents

Introduction

In 2010/11 Ageing, Disability and Home Care made a commitment that advocacy and information providers would have the opportunity to examine the implications of person-centred approaches for their services.

The commitment relates to the NSW Government's Stronger Together 2 reform of the disability service system, which will give people with a disability more control over their lives, including how the specialist disability system supports them.

To progress reform, the NSW Government has allocated more than $141 million over the next five years for decision support resources, including information, planning, advocacy, case management and service brokers.

This resource book was developed following a workshop in June 2011 for representatives of advocacy and information services in NSW. In supplementing learning from the workshop, it is designed to:

- promote a greater understanding of person-centred approaches by these services
- assist them to examine their work with service providers
- prompt reflection on the implications for their work.

Publication of the resource book is a step towards bringing people with a disability to the centre of decision-making about their lives today and in the future. This approach, which is has been internationally recognised, is particularly relevant for people from culturally and linguistically diverse backgrounds and those of Aboriginal and Torres Strait Islander descent.

Ageing, Disability and Home Care will be consulting extensively with people with a disability, their families, carers and service providers and other stakeholders about the implications of person-centred approaches for service delivery, including the changes needed to personalise support.

Why work in person centred ways?

Person centred approaches help people get better lives. An advocacy service can advocate for this. An information service can inspire people to have this. Both advocacy and information services can influence disability and other services to work in person-centred ways.

Person centred approaches can mean that people with disabilities have better lives. That means having:

- a real home
- a meaningful week
- purpose
- family, friends and acquaintances
- growth and self development
- social groups to belong to
- people treat you as an individual
- control over the direction of one's life and future
- good health
- a belief system
- safety, security and justice

What does it take?

International literature [1] and the experience of practitioners, families and people with a disability indicates that significant and positive changes to the lives of people with a disability are more likely to come about when:

- Specialist disability services are willing to review their own practices and focus on the future, not the past. They place more importance on offering beyond current practices and tailoring supports to meet the needs of individuals, instead of fitting the person into what they have done in the past.

- There is strong leadership driving the service to change its values and the way it thinks about bringing individuals and families to the centre of decision making about their own lives and futures.

- There is knowledge and information available about person centred approaches. There is agreement that all parts of a service need to be involved in the changes to practice that result from implementing person centred approaches. This ensures that there is not just a superficial adoption of person centred approaches but provides everyone in the organisation with the skills needed to change the way they have traditionally responded to people with a disability.

- There is a genuine partnership with people with a disability and families. The service encourages individuals and/or families to own their futures and goals and the service works to make sure that the person's plans for their future are translated into action.

- There is a commitment to change the ways that funding is used, to seek different forms of funding that provide greater opportunity to implement person centred approaches, and to work to transform block funding into flexible individualised funding.

"In order to support the kinds of community changes necessary to improve people's chances for a desirable future, virtually all existing human service policies and agencies will have to change the ways they regard people, the ways they relate to communities, the ways they spend money and the ways they define staff roles and responsibilities." [2]

Advocacy and information services are crucial to ensuring that people with a disability can make life decisions which reflect their individual identities, interests and needs. This role involves direct advocacy with, and for, them at service provider and broader systemic levels. It also entails providing relevant and accessible information about the disability service system and about what is possible in their lives.

[1] Ellis. J., Sherwin, J., van Dam,T., (2008) Person Centred Planning: A review of the literature, Department of Ageing Disability & Home Care

[2] Valuing People – A New Strategy for Learning Disability for the 21st Century – Guidance for Implementation Groups http://valuingpeople.gov.uk

Definition

The term "person-centred approach" is best explained by looking at what it means for both people living with a disability and what it means for the organisations providing services to them and their families.

Person-centred approaches give people with a disability:

- valued roles
- participation and belonging in the community
- freely given relationships
- greater authority over decisions about the way they live
- genuine partnership between the service, themselves and/or their family and allies
- individualised and personalised support arrangements.

Person-centred approaches require that organisations:

- have a committed leadership that actively instils the vision of a person-centred approach at all levels
- have a culture that is open to continual learning about how to implement a person-centred approach
- consciously hold positive beliefs about people with a disability and their potential
- develop equal and ethical partnerships with people with a disability and their families
- work with people to individually meet each person's needs so that they can be in valued roles in valued settings
- develop appropriate organisational structures and processes

The elements of a person-centred approach

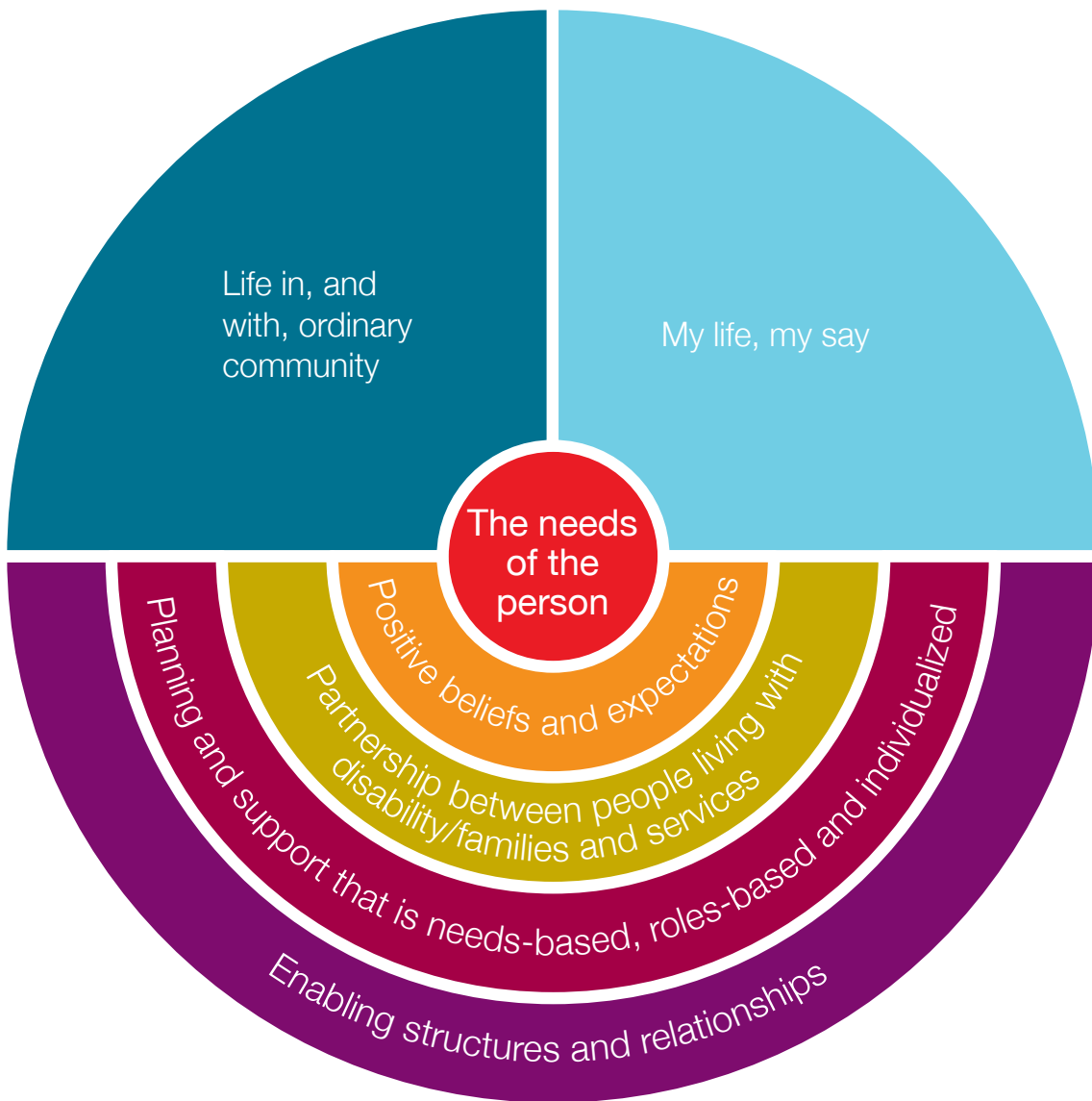The following sections explore the seven elements of a person-centred approach:

1. The needs of each person
2. Life in, and with, ordinary community
3. My life, my say
4. Positive beliefs and expectations
5. Partnerships
6. Planning and support
7. Enabling structures and relationships.

Each section highlights potential challenges for advocacy and information services. They also include reflection questions to help services consider their work practices.

How the elements fit together

Working to help people with a disability experience a good life through a person centred approach starts with understanding and meeting the needs and wishes of the person so that they experience a life in and with ordinary community. This is an ordinary life where they have authority over their life and support arrangements. Having an ordinary life in and with community and having authority over their lifestyle and support arrangements should be the outcomes of a person centred approach.

Achieving this requires all people to hold positive beliefs and expectations. Crucially, it requires services to work in partnership with individuals and their families/allies. Planning and support needs to be individualised and based on an individual's needs and hopes for valued roles. For person centred approaches to work, organisations need to develop enabling structures and relationships.

Life in, and with, ordinary community

My life, my say

The needs of the person

Positive beliefs and expectations

Partnership between people living with disability/families and services

Planning and support that is needs-based, roles-based and individualized

Enabling structures and relationships

The needs of each person

What this is about

Understanding and responding to people's immediate and fundamental needs is central to working in person centred ways. An accurate understanding of needs will come from an appreciation of the humanity of each person with a disability. Rather than focus on deficits, the key question is: what are the needs that must be met in order for the individual to have a typical, yet rich and meaningful, life.

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What works	What does not work
Considering whether a person will have needs relating to their disability e.g. mobility if they have cerebral palsy.	Thinking about the person mainly in terms of what they cannot do.
Considering whether a person might have needs stemming from past experiences, e.g. a need for acceptance stemming from past rejection.	Listing the deficits e.g. inability to read, walk or eat independently.
Considering whether a person has needs arising from their vulnerabilities, for example vulnerable to abuse, rejection, isolation.	Accepting that the person has identified all their needs. They may define their wants but be unable to articulate fundamental needs.
Considering whether a person has needs arising from their cultural or linguistic background.	Focusing on the present e.g. identifying that a person "must learn to cook".
Making sure the person and their friends and family are central to identifying needs.	
Focusing on the future e.g. identifying that a person will need to cook in their own home.	

Potential challenges

Accurately identifying and considering universal human needs and needs which arise from a person's past experience and from their disability.

Determining whether there is a difference between what a person with a disability says they want and what service providers say they need, and their actual needs.

Influencing services so that they do not focus on the person's deficits.

Questions for reflection

If you work with an advocacy or information service:

- What dilemmas do you face when advocating for, or providing information to, a person whose disability or life experience impairs their ability to say what they really need? This includes big decisions about their desired future.

- Do you give a person with a disability information about community-based, mainstream organisations which could strengthen community connections and reduce reliance on disability services?

If you work with an advocacy service:

- What questions would you ask disability service providers about:

  - How they identify the complex needs of each person?

  - How they would respond to these needs?

- What advice would you offer a service provider about identifying the needs of a person living with disability?
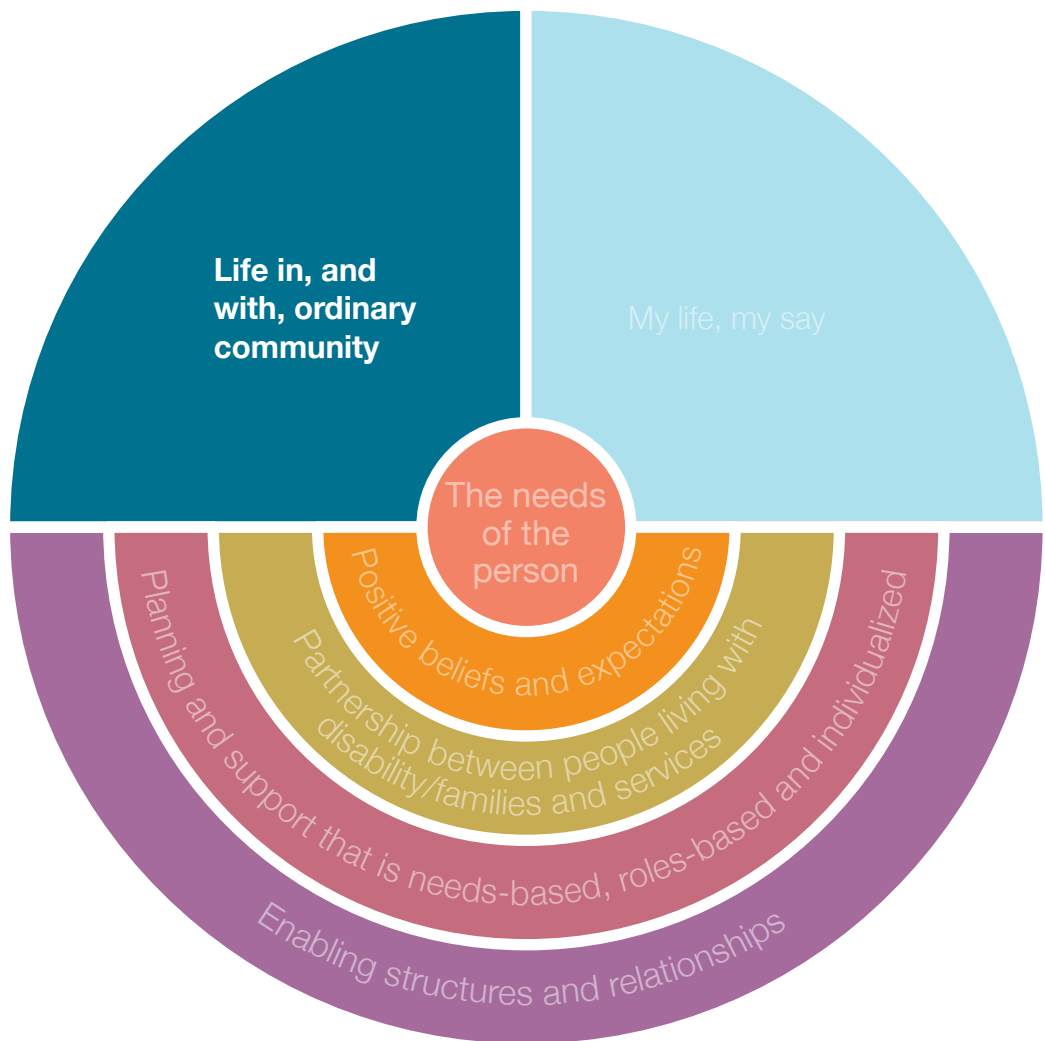
If you work with an information service:

- What should you know about:

  - How a disability service provider identifies the complex needs of each person?

  - How they respond to these needs?

- Do you pass this information to the person or their family so that they can decide whether to approach the service provider?

- What do the answers to these questions mean for your work?

Life in, and with, ordinary community

What it means

"Life in, and with, ordinary community" refers to where and with whom people spend their time. Other terms commonly used include: "social inclusion", "social integration", "social participation", "'good' lives", "typical lives" and "rich and meaningful lives". This is a key outcome of working in person centred ways.

Life in, and with, ordinary community

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What it is	What it is not

Life in, and with, ordinary community is a combination of:
 	
- participating in community life
- being valued, e.g. as a tenant, host, neighbour, family member, employee, volunteer, club member
- having:
  - a range of social contacts
  - friends
  - a way of contributing
  - a reason to get out of bed each day
  - a real home
  - meaningful work
  - hobbies
  - freedom to make decisions
- being listened to
- experiencing fun and joy
- using mainstream resources e.g. libraries, sports facilities, clubs, interest groups.
	A service life, as seen when a person:
	
	- lives or spends time in a disability centre located in the community.
	- has the role of 'service client' as the main role in their life.
	
	Occupying a bed in a house.
	
	Living in a community, but not participating in community life.
	
	Always visiting community services in a group.

Potential challenges for advocacy services

The complexities of advocating that a person with a disability to receive personalised support to live in the community.

Potential challenges for information services

The difficulty of wording information to clearly convey that people should be able to live in, and with, ordinary community.

Questions for reflection

If you work with an advocacy or information service:

- To what extent should you help people and their families to understand the difference between living in a group home and living in, and with, ordinary community?
- How can you bring providers to a common understanding of what "life in, and with, ordinary community" might look like?
- What are the dilemmas in referring people to service providers that do not use person-centred approaches?
- How can you assist people to find and access mainstream community organisations through which they can pursue their individual interests?

If you work in an advocacy service:

- What dilemmas do you face if the services needed to support a valued role in the community are not immediately apparent?

'My life, my say'

What it means

"My life, my say" refers to the importance for everyone of having a level of authority over their lives. For people with a disability, this means not only about control over lifestyle, but also a negotiated level of authority over support arrangements. This is a key outcome of working in person centred ways.

What it is	What it is not
Asking the person what they would most like.	Following everything the person says they want.
Enabling people to have lots of experiences so they can make informed choices.	Following nothing the person says they want.
Thinking not only about choice, but also about how people can have more control in their own lives.	Making decisions for the person about everything.
Ensuring that a person who finds it hard to make good decisions is supported properly.	Telling a person what the decision is after it has been made.
Providing information so that people can make informed decisions. Involving family and allies to assist with decision-making.	Expecting that people will immediately be able to make good decisions without support
Connecting the person/family to others who have been able to take some authority over their lives.	
Giving people a say over their support arrangements e.g. the staff, the time they come and what do they do.	

Potential challenges for advocacy services

Enabling people to make informed decisions when they have impaired capacity or little or no experience of a 'good' life.

Supporting their choices, especially when these choices may lead to harm, particularly for people with impaired decision-making capacity.

Defining the role of family and loved ones, especially if the person has impaired decision-making capacity, or is a child or young person.

Questions for reflection

If you work with an advocacy or information service:

- How can you discover the barriers affecting a person's ability to control their own life?

- How can you learn about their past experiences and the effect of such experiences on the way they express their needs?

- What kind of relationship should you have with service providers to best ensure that the person has a real say over their own life?

- How can you learn which providers respond to the decisions of a person and/or their family more flexibly and personally?

- What weight should you give to cultural differences which could affect how a person might like to control their life?

If you work with an advocacy service:

- How can you ensure that you focus on the person, listen carefully to them and assist them to make decisions which will bring them positive roles in the community?

- To what extent do you involve family, friends and others close to the person in decision-making?

Positive beliefs and expectations

What this means

There is a link between what we believe and our actions. What we believe can be conscious or unconscious.

It is essential that all people who promote person-centred approaches believe that a 'good life' in, and with, community is achievable for all individuals, regardless of their level of disability.
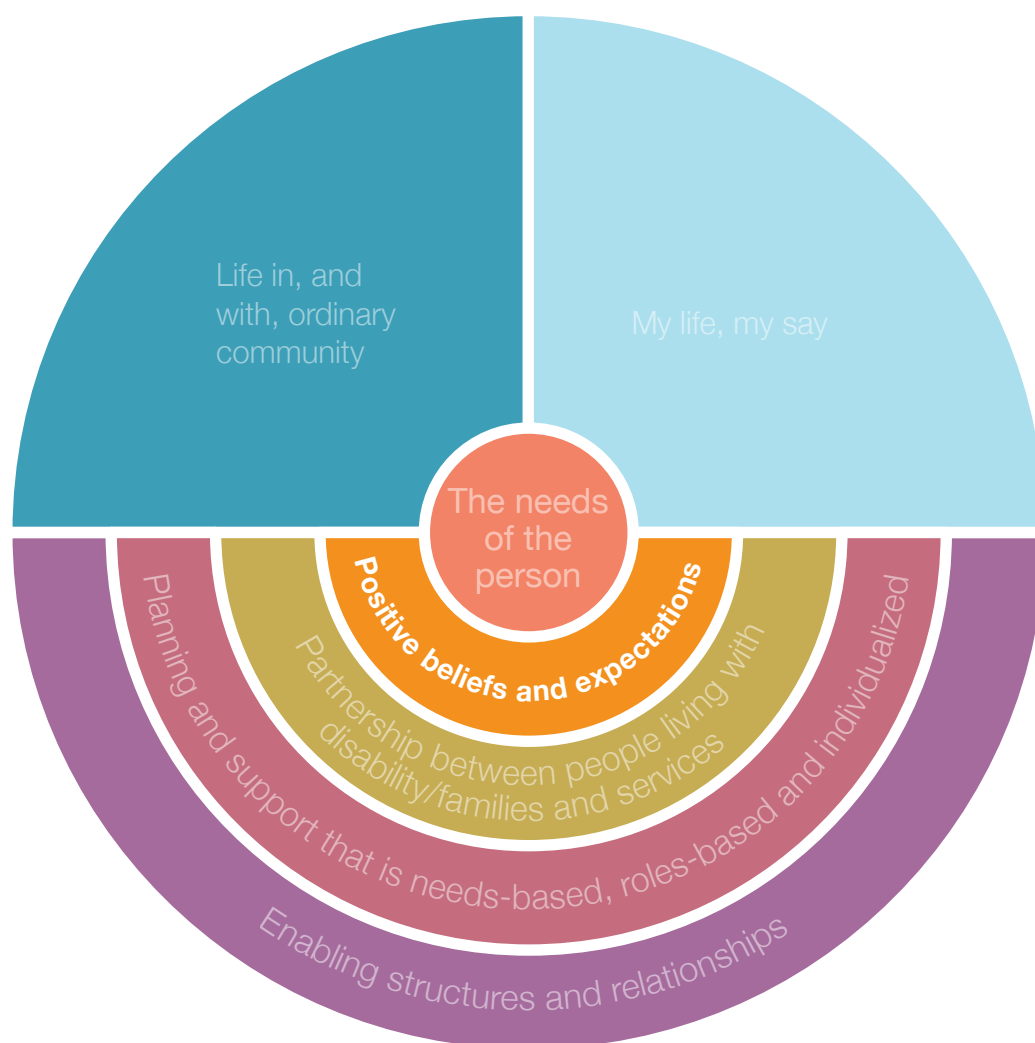
Beliefs and expectations consistent with person-centred approaches	Beliefs and expectations inconsistent with person-centred approaches
Everyone: ■ is born into a common humanity and deserves a 'good' life ■ needs to belong to a group on the basis of their shared humanity, not on the basis of their disability ■ needs support, some more than others ■ can learn and communicate ■ has the inherent right to determine their own future and make informed decisions. A service can assist people to: ■ participate and belong in the community ■ have freely given relationships.	Having a disability means that people cannot have lives like other people Having a disability means having more in common with each other than with other citizens Only paid disability workers can meet the needs of people living with disability Families cannot be an equal partner with a service.

Potential challenges for advocacy services

Ensuring that a service's board, management and staff hold positive beliefs and expectations about people with a disability.

Establishing whether service providers hold positive beliefs and expectations about people with a disability and that these carry through to their work.

Questions for reflection

If you work in an advocacy or information service:

- What would you look for in a service, beyond what they say they believe, to show that they support people to have better lives and are involved in decisions about their own lives?
- To what extent do your service's mission and vision statements reflect positive beliefs and expectations of people with a disability?
- How do you review whether values and beliefs are reflected in actions?
- What knowledge and experience do staff need to have to raise the expectations of people with a disability about the services they receive?
- Do the criteria for vacant positions spell out the values to which the organisation is committed? What questions are asked at interview?
- Are there opportunities for board, management and staff to identify what is needed to ensure people with a disability can enjoy a full and productive life?
- How does the service determine whether providers hold positive beliefs and expectations?

If you work in an advocacy service:

- How can you work with providers to address gaps between what they say they believe and expect and what they do?
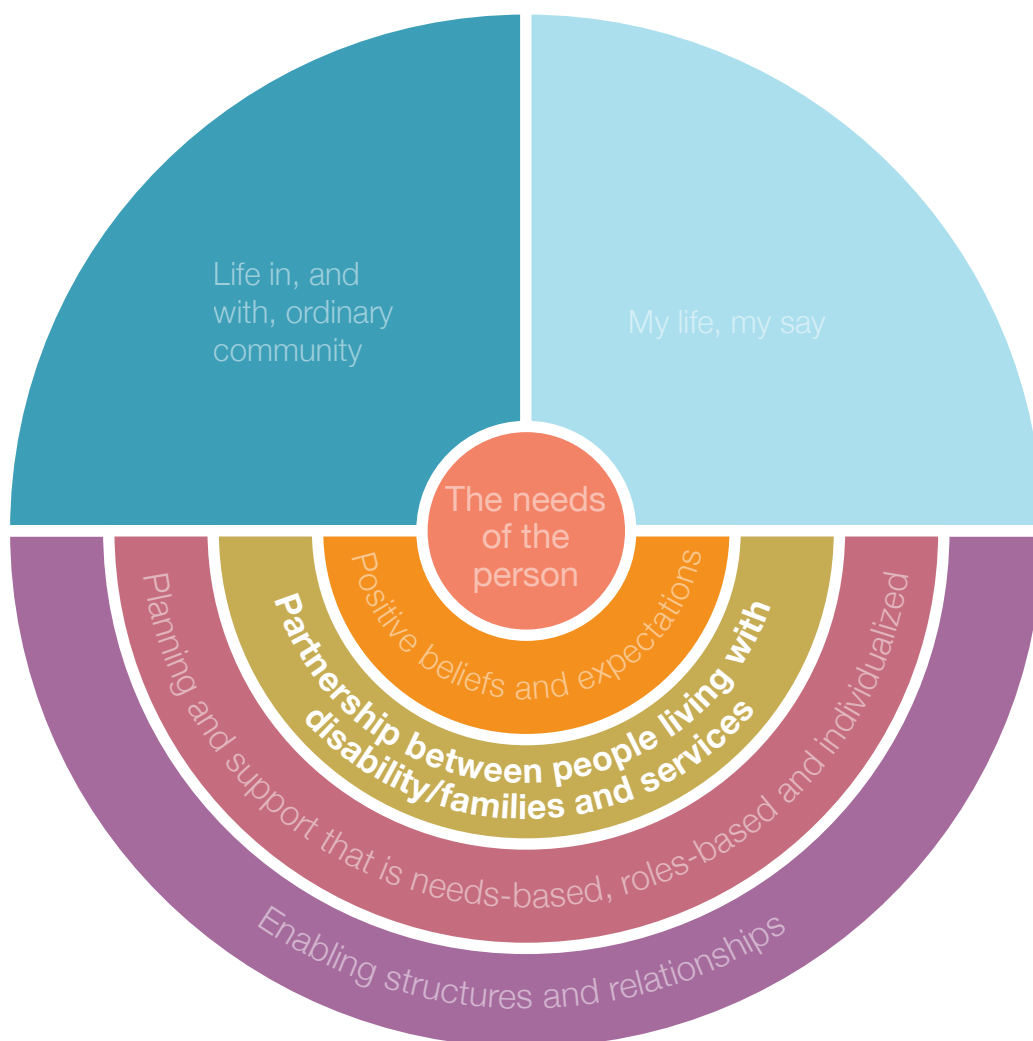
If you work in an information service:

- In what ways do you raise the sense of what is possible in people's lives through your phone calls, publications or workshops?

Partnerships

What this means

Genuine partnerships between people with a disability and services help the former stay in charge of their own lives and ensure they have the right support arrangements.

The needs of the person

Life in, and with, ordinary community

My life, my say

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Enabling structures and relationships

What happens with partnerships	What happens without partnerships
Professionals and the person living with disability and/or their family share power, knowledge and information.	Professionals hold all power due to their status and access to resources.
The service recognises that the person/family has important knowledge about their own needs, and about how these are best met.	Professionals become the decision-makers by default.
The service provider negotiates with the person about how needs should be met.	Professionals control what happens to the person
With constructive communication, an alliance is created at both an interpersonal level and a practical level.	Service recipients are disempowered and frustrated.
There is information sharing and collaboration on all major decisions.	
Trust is built when the service delivers on promises.	

Potential challenges

Entering a genuine partnership where authority is shared, each party respects and listens to the other and everyone work together on decisions.

Determining the best relationship with the family or loved ones, especially when disability impairs the capacity of the person to make decisions or when they are a child or young person.

Building people's confidence and ability to make decisions and exercise authority over their own lives.

Questions for reflection

If you work with either an advocacy or information service:

- In what ways can you partner more with people with a disability and their families?

- To what extent are staff assisted in exploring who holds power and how to collaborate on decision-making?

- How can people with impaired decision-making ability be given relevant and accessible information and encouraged to come to their own conclusions?

- How can services ensure that people have access to all relevant information, including people from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander communities?

- How can the service support people to participate in discussions about what they need to achieve a meaningful life?

- How does the service assess whether it is has given a person sufficient support to be the 'author' of their own future?

- How can the service encourage providers to establish partnerships with people and/or their families?

Planning and support

What this means

There are three features of planning and support essential to a person-centred approach:

1. It should be needs-based, as explained earlier in this booklet.
2. It should be roles-based. This means that the support service should enable people with a disability to have valued roles in the community.
3. It should be individualised. This means that, instead of following a standard process, the service should tailor support to each person's lifestyle aspirations, while being mindful of their vulnerabilities.

Strategies more likely to be person-centred	Strategies less likely to be person-centred
Needs based Identifying the needs essential to a good life. Understanding that needs are those shared with other humans. Recognising that some needs arise from the person's disability or past experience.	Fitting the person into what the service has on offer (the menu). Seeing needs in the context of the person as a service client. Negatively labelling needs e.g. autistic, challenging behaviour. Seeing needs in basic terms only.
Roles based Supporting the person to have valued roles in the community.	Supporting the person only in the role of service client or other non-valued roles. Fitting the person into activities and programs.
Individualised Responding in a highly personalised way. Ensuring responses are relevant to what the person needs. Tailoring responses to needs e.g. what is done, by whom and where.	Confusing having personable staff with working in a person centred way. Confusing working in a one-to-one relationship with working in a person centred way. Offering the person the same program as others. Offering individualised support that is not relevant.

Potential challenges

Gaining a deep understanding of the meaning and importance of valued roles.

Understanding what supporting someone in a needs-based, roles-based and individualised way means in practice.

Advocating for a person deeply entrenched in a service that uses a group-based, building-based model and is unwilling or unable to change.

Ensuring that everyone in the organisation understands that working one-to-one with people does not necessarily mean it is person centred.

Questions for reflection

If you work with an advocacy or information service:

- to what extent does the service promote valued roles for each person? (See the section Life in, and with, ordinary community.)
- how can the service influence providers so that the planning process:
  - starts with the dreams and interests of each person?
  - ensures that the person has sufficient information and experience to make informed decisions about their future?
  - critically examines how each person can pursue their interests, become a valued community member and develop friendships and other freely given relationships?
  - identifies and tries to overcome the effect of negative stereotypes and expectations?
  - identifies and responds to pressing needs?
  - shifts from 'doing activities' to assisting the person to pursue roles and relationships in the community[3]?
- how does the service respond to problematic support arrangements which arise from a lack of planning by providers?
- to what extent can the service influence planning so that support arrangements are:
  - built on the strength of people and their families and friends?
  - relevant to the needs of the person?
  - tailored to give the person and/or their family a say?

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[2] Ramsay, S., (2007) Roles Based Planning: A Thoughtful Approach to Social Inclusion and Empowerment, International Social Role Valorization Journal, 2 (1), 4-12.

Enabling structures & relationships

What this means

Structures can be thought of as an organisation's systems and procedures. Often service providers require significant structural and cultural change before they can successfully implement person-centred approaches.
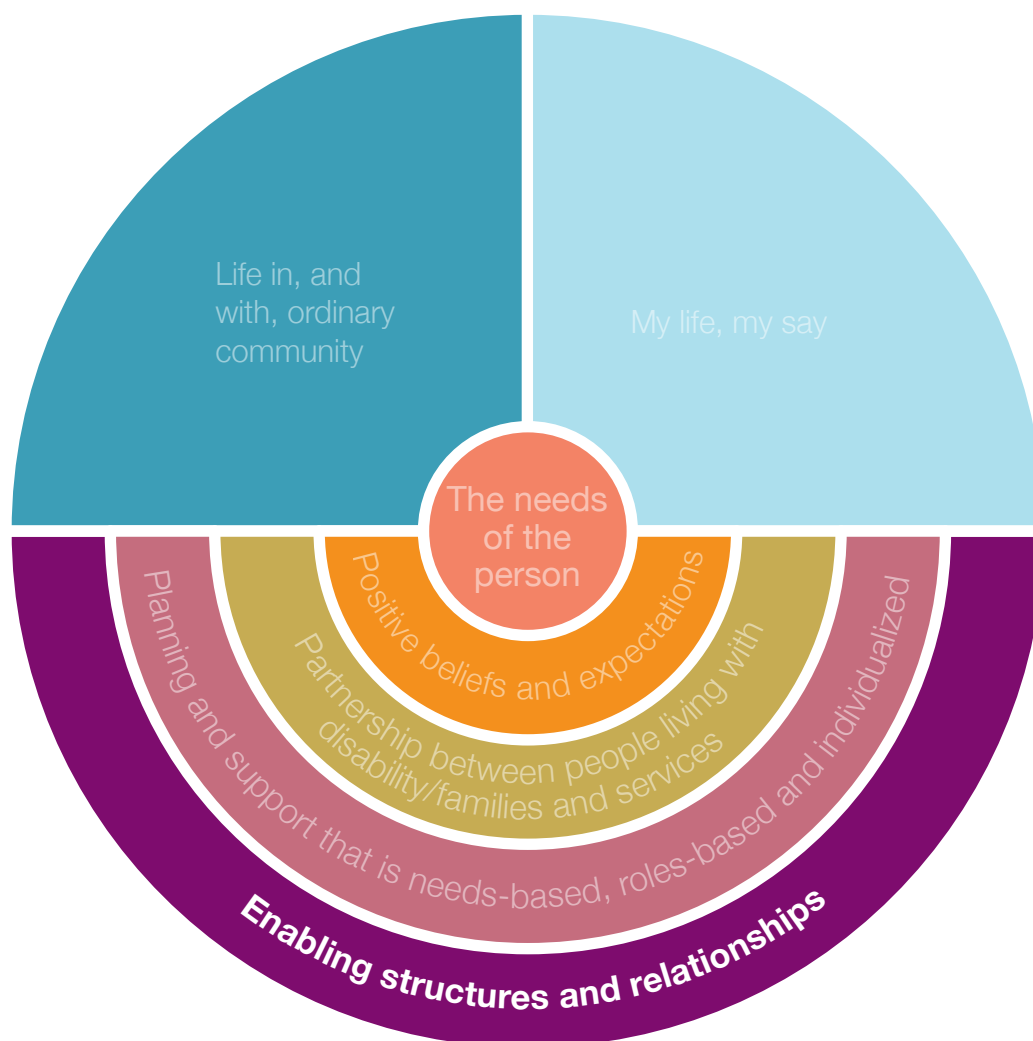
Organisational elements to consider in implementing a person-centred approach	System/procedural aspects to consider in implementing a person-centred approach
Organisational structure	▪ Delegation ▪ Decision making ▪ Level of bureaucracy.
Finance	▪ Budgetary processes ▪ Feedback to families/individuals.
Vision	▪ Strategic planning ▪ Decisions about obtaining funding which is more likely to lead to person centred approaches ▪ Transformation.
Human resource management	▪ Recruitment ▪ Supervision ▪ Role descriptions ▪ Working conditions.
Culture	▪ Preparedness to change ▪ Commitment to open communication ▪ Continuous learning.
Interface with people	▪ Organisation of meetings, including where they are held and who attends ▪ Planning tools used. ▪ Reviewing and acting on agreed plans
Relationships with people with a disability	▪ Nature of partnerships ▪ balance of power ▪ Role clarity ▪ Capacity of senior people to understand the people they serve.
Bricks and mortar	▪ Buildings that group people vs using valued settings

Potential challenges

Advocating for service providers to be less rule-bound and to individually tailor their responses.

Acting in the best interests of a person with a disability when advocacy and information roles are combined with that of service provider.

Questions for reflection

If you work in an advocacy or information service:

- how does the service remain independent of the providers it is trying to influence?
- how can a service optimise its independence?
- does your organisation's mission and vision reflect a commitment to change traditional approaches to people with a disability?
- how is the person and/or their family assisted to:
    - think through new opportunities?
    - negotiate with the service provider for more a flexible and personalised response?
- how could the service discuss the need for enabling structures and systems with providers?

If you work in an information service:

- how does the service assist a person and/or their family to understand the way a provider operates?