Good ideas for better lives

by Jane Sherwin

A booklet of good ideas, for people who want to make a difference

Out of concern for 'Un-lived lives'

Fortunately for many of us, we often get to bask in many moments of reciprocal love, feelings of a job well done, the warm feeling of a stable and welcoming home, the security of knowing that at least one other person looks out for us, and the excited anticipation of something in our future whether it's more love, a new job, a new friend or a holiday.

I sometimes think about the parallel universe that many people with disabilities and older people exist in: separate schools, workplaces, homes, and recreational places. Or stuck at home with workers in and out of the front door, but without connection to the neighbourhood, to the past, and to the future.

What must it be like for those who are marginalised to be on the outside looking in at others. Those others, even though they might complain about being overly busy and concerned about their finances or health, manage to have access to many of the good things in life: relationships, love, belonging, a home, reasons to get out of bed each day, ongoing chances to learn and to 'stay sharp', a sense of a future, a sense of control over what is happening in their lives, moments of joy, and receiving respect.

My sense of 'parallel lives' speaks to people's exclusion from the typical world. Adam Phillips suggests a similar-yet-different idea. He said, 'All of us lead two parallel lives: the one we are actively living, and the one we feel we should have had or might yet have.'

This makes me also think about the 'un-lived lives' of many people with disabilities and older people. What must it be like to be underestimated? To be viewed as someone other than who they really are, like a burden or menace or better off somewhere else? To be understood only through the lens of a label or diagnosis?

If you, dear reader, feel concern and even outrage at these descriptions, do please read on.

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Dear Reader,

This booklet of fifteen good ideas was written primarily for paid workers and their supervisors, and could also be of interest to individuals and family members. The intent is not only to provide brief and easily read information, but also to be a basis for conversations. Each 'good idea' topic consists of three sections:

- an explanation of what the idea means
- a description of why the idea is important
- reflective questions that form the basis of a conversation or individual reflection.

Quotes are provided to also shine a light on each idea.

The term 'people with impairments' is used so that the reader who is involved with either people with disabilities or older people will find the writing relevant to them.

Many of the ideas are informed by Wolfensberger's theory of Social Role Valorisation, and some from the work of Michael Kendrick. My confidence in knowing how important these ideas are and how practical they can be is based on my forty years of commitment, personally and professionally, to people with impairments and families.

All feedback is welcome.

warm wishes

Jane

"Imagine all the people living life in peace. You may say I'm a dreamer, but I'm not the only one. I hope someday you'll join us, and the world will be as one"

(John Lennon)

"Quality means doing it right when no one is looking." (Henry Ford)

Good idea 1

Do the 'right thing'

What is meant by doing the 'right thing'?

The right thing is not just one thing.

The 'right thing' is helping people with impairments have a rich and meaningful life that is purposeful for them and includes valued roles and rich relationships with a range of people. It is also helping people have a sense of control over the things that matter to them. It is helping people put their best foot forward so that that they are given the respect they deserve. It is the difference between merely 'existing' in life and, instead, thriving. Even for those who are facing the end of their lives, it means helping the person live as good a life as possible, until they are no longer breathing.

The right thing is about helping people have real homes not a facility or a workplace. It is about helping people make friends of their own and not be marginalised in community. It is about helping people have real jobs and real passions, learning and thriving.

The 'right thing' avoids wasting people's time or making them look foolish. It is about not taking over their lives. It is about not getting in the way of their relationships with family and friends.

To do the right thing, we need to be very aware of our thoughts and actions. This takes mindfulness and self-critique. It is necessary to hold a belief in the shared humanity of people with impairments and in the 'rightness' of people living ordinary lives, even if it takes extra-ordinary efforts.

"Quality is never an accident; it is always the result of high intention, sincere effort, intelligent direction and skilful execution.
It represents the wise choice of many alternatives." (William A Foster)

"We learn, when we respect the dignity of the people, that they cannot be denied the elementary right to participate fully in the solutions to their own problems. Self-respect arises only out of people who play an active role in solving their own crises and who are not helpless, passive, puppet-like recipients of private or public services." (Saul Alinsky)

Why this idea is so important

Talking about the 'right thing' is talking about offering a service of quality. Quality is sometimes thought to exist if all the policies and procedures look polished and that the audits are passed. These things are important but 'lived quality' is essential. In other words, people's lives should be enhanced if a service is in their lives. A service has a responsibility for making these positive differences and are accountable to the individuals with an impairment to make this happen.

Questions to ask yourself

For reflection

In what ways do my efforts help achieve 'quality'?

- Which needs am I trying to meet? Have I thought about their human needs (like to belong, to be well respected, to learn and grow) as well as needs related to their impairment (like to be able to get around, to communicate, to be healthy)?
- Do I meet an individual's needs in relevant and effective ways
- Do I work in ways so that they maintain their sense of autonomy
- Do they have access to the good things of life?

For action

What should I do more of? What should I do less of?

Good idea 2
Be 'of service'

Why this idea is so important

For generations, community has said to services, 'take these people (with impairments, like disability or old age)' and 'look after these people because they cannot look after themselves'. Sometimes what community said was, 'Take them because we do not want them'. Unfortunately, services have said, 'yes'. This has led to many people with impairments being 'in' a service, with 'service lives', separate from 'community lives'. This includes individuals who live in their own homes, yet their lives are still dominated by service decisions such as who the workers are, when the workers arrive and what they can and can't do.

What is meant by be 'of service'?

Being OF service is very different from being A service. The difference is that in being 'of' service, the role of the service worker is to enable and facilitate solutions to the person's issues that are truly relevant, responsive and individualised. Those solutions should also lead to the individual having a lifestyle that is authentic to them, not imposed by the service using a menu of service options.

When being 'of' service, the objective for the worker is to listen in order to learn and to understand about the person or issue, and to co-create what the solutions might be. This is different from listening in order to find a service-led solution. The objective is to guide without taking over and to find examples of possibilities and growth, not to keep people stuck in the same patterns of dependent life. Ultimately, being 'of service' is about making a positive difference in people's lives.

> "We sometimes have to make ourselves small so others can be big. I have to give up a few things in order to be 'small' – a bit of my ego, attention, center stage, the role of champion or even 'hero' in the life of another, but I can afford to give these up ... I have a few people in my life who have modeled this for me and, when you see it, it is exquisitely beautiful and unmistakable. The direct result can be the unfolding and revealing of another human being, who may never have been fully seen or acknowledged." (Betsy Neuville)

In particular, the role involves working in ways such that the person retains their sense of being the 'makers of their own destiny'. If the individual must 'fit in' to the service menu of 'solutions', then the risk is that the solutions will be less than ideal. For example, an older person who was expected to fit into the menu of a community support service found that even though the garden was extremely important to her, she could not employ a gardener but could ask the person who showers her to also turn the hose on. This demeaned the importance she placed on her garden and reduced her sense of being a gardener.

Sometimes people think that doing 'for' people with impairments is the kindest and most helpful thing that they can do. Sometimes, like when the worker or family member is busy, they might actually do 'to' the person. Unfortunately, neither of these ways are being 'of' service as they take away the person's autonomy and skills.

Being 'of' service means that staff are asked to be humble, to know the person well and to help the person find a life that sees them thrive. It requires service workers to set aside their egos and not need gratitude or status.

Questions to ask yourself

For reflection

To what extent is your role one where you are alongside the person, enabling them to be the best that they can be?

To what extent is your role one where the priority is that you have a range of tasks to get done? Or perhaps it is one where the person has had to choose from a service menu even though it is not a really good fit for what they like or need?

What beliefs could you hold in your mind and heart so that you were more likely to be 'of service'?

For action

Now that you have identified helpful beliefs which could lead to being 'of service', what are three things that you could do to turn the beliefs into action?

Good idea 3

Create and nurture 'power-with' relationships between workers and the person and their allies

What is meant by 'power-with' relationships?

'Power-with' refers to a relationship where the power is shared. In a power-with relationship, it is recognised that the person/family brings a set of knowledge, experiences and resources to the table that are valid, and crucial for any collaborative efforts. These are forms of power that have been traditionally ignored and led to unequal power relationships.

A guiding assumption is that any person, including someone who is marginalised, has innate power that should not be taken away eg through not being involved in key decisions or having service solutions imposed on them. Another guiding assumption is that both parties should bring respect and a willingness to have meaningful and constructive conversations, and that both parties should collaborate to create a lifestyle where the person thrives. To do the right thing, we need to be very aware of our thoughts, words and actions. This takes mindfulness and self-critique. It is unfortunately possible to say that one is respectful, yet act in ways that exclude people from decision making.

Why this idea is so important

A power-with relationship leads to:

- individuals with an impairment feeling empowered rather than disempowered
- an experience where they have been listened to and learnt from, rather than the 'experts' knowing best
- the person shaping what happens in their own lives
- the person being more likely to be committed to whatever 'solutions' are agreed to, because they have had a say in it.

If both parties are willing to put effort into a power-with relationship, then not only can that type of relationship be created, it can also be repaired at times of disappointment or frustration.

'Power-with' contrasts with a power-over relationship. In the latter, it is the service that decides what each person's lifestyle is, who they might spend time with, where they spend time, the rules of a home environment and the patterns of life.

This is not to say that the staff aren't kindhearted; it is to say that these ways have taken the power and control away from the individual and their family. This has led to frustration and a sense that the person has been 'handed over' to the service.

"'Right relationship' is an ethical condition that is mutually created between services and those persons and groups whom they serve … It exists when the people served are seen and treated with appropriate respect, integrity and value and where they are enabled to be decisively influential in how they are to be assisted and where the service and those who conduct its work are also similarly treated by them in a reciprocal manner." (Michael Kendrick)

Questions to ask yourself

For reflection

Reflect on the relationship you have with any one individual. In what ways do you listen with an open mind and heart so that you are learning what the person is truly saying? In what ways do you frame questions and suggestions so that the person feels like they are steering their own course and owning their own solutions?

For action

Try to be more present, physically and emotionally, in a relationship with a person with an impairment. For example, what would it take for you to be less judgmental? What would it take for you to listen to understand, and not listen primarily in order to solve problems?

Think about how the person expresses their opinions, wants and desires. What can you do to assure them that they've been heard?

Good idea 4

See the person as 'same as'

We "need to emphasise the 'ordinariness' of disability. We need to forget the 'labelling and packaging' process. What has to be remembered and stated quite categorically and unequivocally is the simple fact that we are people/human beings!" (Mike Duggan)

What is meant by 'See the person as 'same as''?

The 'same as' idea says that people with impairments are first and foremost unique and valued individuals who have the same rights as other citizens and the same desires for fulfilling and meaningful lives.

In other words, the starting assumption is that an individual with an impairment is more likely to have things in common with (rather than be different from) other people of the same age, gender and culture. This is also relevant to those who acquire an impairment through age, disease or accident. The person, despite changes in abilities or looks, has the same essence as they were before: someone's partner, parent, sibling, friend, acquaintance and citizen.

Why this idea is so important

Alternative thinking sees people being viewed as thinking that people are the 'same as their label'. Thinking this way means that we lose sight of who each person really is: a person with a unique personality, history, culture, and preferences. More importantly, what they have in common with others are things like shared culture, family history, and a longing for the good things of life.

Unfortunately, people with impairments are likely to be seen as the 'same as' other people with the same label or diagnosis such as the 'CPs', 'the wheelies' or 'the dementias'. Just as all people with blue eyes are not the same, neither does having Down syndrome make the person the same as other people with Down syndrome. Similarly, a person who has had a stroke is not the same as other people who have had strokes.

Another assumption applied to people with impairments has been that people are the 'same as' their IQ, such as 'he has the mind of a two-year old'. This is very unhelpful as it leads to treating people as children forever (or in their second childhood) and also leads to not providing them with learning opportunities and age appropriate experiences.

The aspects of a person that we focus on shapes how we see them and treat them. Sometimes we only see those characteristics that appear to make a person different, like their different facial features, or different way of communicating, or learning or behaving or health issues. Those things are real; the idea of 'same as' is not saying to ignore those things. Rather, the idea is saying to not assume that those things equate to who the person is and what they have in common with others.

Questions to ask yourself

For reflection

Think of a person with an impairment you know well. What blinkers might you have on that stop you from seeing that he or she is a human being with a life to live? What is your role in helping the person become the person that they truly are and have potential to be?

For action

Listen to the words that you use. Tune into what hopes you have for a person. Are these actions coming from perceiving them according to their age, gender and culture or coming from focusing on their impairment?

How would anyone ...

... get a meal if they can't cook?

- frozen meals
- family help out
- learn to cook
- go to a pub/cafe
- friend brings food to share

Good idea 5
Think typical

What is meant by 'think typical'?

A short-hand reminder to us when we are trying to work out what might help in the lives of people with impairments (through age or disability) is to 'think typical'. This means that we can ask ourselves, 'how would anyone else who doesn't have an impairment get (a particular) need met?' It is especially important to 'think typical' when creating a picture of a good life and positive future, and when working out what might assist a person.

For example, if someone with an impairment is creating ideas for themselves about life in five years time, the aim would be to think about what the life of someone of a similar age, gender and culture looks like. Or if someone was looking for somewhere to live, the question becomes 'how would anyone else find a new home?' The answers to that question are things like: look on-line, in the newspaper, on local notice boards, think about the best neighbourhood that is affordable and near resources, think about who best to share with based on personality etc. This is very different from finding a vacant bed in a residential home. Other examples of 'think typical' questions are, 'how would anyone else find a friend?', 'how would anyone else pursue an interest in art' and 'how would anyone else (who is an adult) look like they are adults and not children?'.

A test of 'thinking typical' is, for example, to judge how similar in looks and feel a group home is, compared to a real home. How similar to real work is work in a disability specific workplace? How similar in looks, activities and routines is a special school to a regular school?

Examples of not thinking typical, include when the first option is to use a paid worker to cook the meals, or to use a disability or aged specific group for gardening.

How would anyone ...

... pursue an interest in flowers?

- be a gardener
- join a horticultural group
- be a flower arranger

"When a young man who is dear to me began to have a laundry list of diagnoses attached to him, those who love him took great care to keep tabs on the 'typical desired teen life' ... Attending special classes, support groups, all sorts of therapies, special schools, lots of drugs, ... these were freely and cheerfully offered by well-meaning people in his life. Those who stood by him never took their eyes off the ordinary, and saw each as something to be carefully and skeptically evaluated, as they are all pieces of the trajectory towards that parallel path. When any were accepted in any measure, efforts to 'strengthen the ordinary' were redoubled – guitar lessons, a course in music theory, ... interesting school projects, time with robust friends." (Betsy Neuville)

Why this idea is so important

Thinking typical requires us, for the moment, to set aside our focus on the part of a person's identity that is directly related to the impairment. If we focus on the impairment, then all we'll identify are disability or aged care solutions that are typically 'special' and exist in 'service-land', not 'typical, ordinary land'. After we 'think typical' and come up with a range of possibilities, then we can think about how to add on strategies that meet the needs related to the impairment.

The 'think typical' idea also leads us to understand that impairment-specific solutions (like a paid disability or aged care worker) should be a last resort, not a first option.

Questions to ask yourself

For reflection

Do I really believe that the needs of someone with an impairment can be met in ordinary typical ways, in typical places, by ordinary citizens? Have I used the default habit of 'disability/aged care' thinking? Or thinking 'typical' first?

For action

Practice 'thinking typical'. How does a child make friends in their neighbourhood? What does a 'good grandson' do? What are the range of ways that someone who loves football gets to be part of the football community?

Write down examples of where you used the 'think typical' way of working. Then list examples of where your mind was in the 'think impairment first' habit. What would it take to change the habit?

Good idea 6

Imagine a 'good life'

"Tell me, what is it you plan to do with your one wild and precious life?" (Mary Oliver)

What is meant by a 'good life'?

The good things of life (for anyone) typically include having family and friends, a home, ways to contribute, a reason to get up each day, belonging, financial security, learning and growth, a say over the things that matter, health and a spiritual life. It also means being respected and accepted. Sometimes 'a good life' is referred to as a 'typical life' just like other people of a similar age, gender and culture, or a 'rich and meaningful life'.

A good life is not about being rich. It is also not only about having choice. A good life is different from having a 'good time', which is what people might enjoy while on holidays and is probably more superficial than what 'a good life' means.

A good life is also very different from a 'service life', which is where the main role of the person is as a client (consumer or customer). A lack of other roles probably is an indicator of few or no friends (without impairments) or ways of being involved in community life.

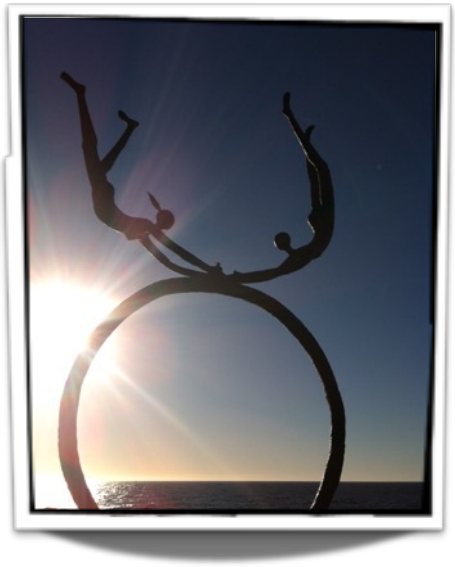
Why this idea is so important

Many older people or people with disabilities don't enjoy a typical, joyful and meaningful life like others of a similar age, gender and culture. Their impairments can lead them to a service life such as a person who lives in a residential home, attends a day service and goes to a segregated recreation group. Or people could be living a marginalised life and be 'stuck' there because this type of life isolates them and keeps them poor. For example, an unemployed person with a disability is often on the margins of society, even if they have service support.

Having a picture of a desirable future (a good life) makes us help people dream big. The imagined picture of a good life is also the filter for all decisions especially when a plan for the future is developed or money is available.

Helping people imagine and get a good life is a way of working for benefits not only for an individual, but also for equity and justice.

High hopes + Think typical: a life like others witout impairments of similar age, gender, culture + The person's strengths, interests, and age → The imagined better life



Questions to ask yourself

For reflection

How clear am I about what the person's picture of a rich and meaningful life could be? Remember to 'think typical' and perceive the person as 'same as', as described earlier in this booklet.

How well am I extending my thinking about what might be possible for and with the person about what their life might look like?

For action

Do some imagining about what a better life might be. Imagine how it could be even better. Share these ideas with someone else.

"All you need is the plan, the road map, and the courage to press on to your destination." (Earl Nightingale)

Good idea 7
Plan for a 'good life'

What is meant by 'plan for a good life'?

Most people plan for important things in their life, like schooling for the children, a holiday, retirement or perhaps a renovation. Some things can happen even without planning.

However for people with an impairment, 'planning for a good life' is a series of intentional conversations. They might start with 'thinking typical' (see Idea 5), such as about how life could be better for the person with the impairment, thinking about those things that are important to the person, and also important for the person. Once there is a sense of a desirable future, the conversation can turn to what it would take to make tithe desirable future happen. Sometimes talk of goals and actions help make the plan more concrete. Intentionality then helps the ideas become reality.

The plan might be about 'life'; these are big picture plans. An example of bigger goals might be for a child with a disability to be in the roles of student, class mate and learner. Other times, the plan might include smaller goals, such as for an older person to maintain their role of gardener by having a seat put in the garden so they can sit to use the hose.

It is really important that the goals actually help move towards the vision of a good life. For example, a skill based goal, like that 'the child will learn to hold a pencil' should support the bigger goal of being in the student role.

If a service is involved, it is important that a plan includes an agreement about how the person with the impairment and/or family would like the service to help them work toward their picture of a good life. Note that the service is not expected to meet all the goals for a good life, but rather only those goals that family, friends and generic services can't meet.

It is also important for the individual and the family to have others alongside them who also share the picture of a good life and the commitment to making it happen. These others could be family or friends, ex-teachers, neighbours … anyone who is committed to the person. What is important is that all members of the planning group should bring hope and optimism about what could happen.

Why this idea is so important

Plans help a good life life happen - for many people, a typical life doesn't happen without a good plan. Instead, people can become stuck in 'disability life' or 'old age life'. The quality of a plan matters: for example, if a person who goes to a day service has a plan, but if that plan simply identifies which of the service activities and outings they will attend, then that is life-limiting. Better planning would consider options to help the person learn and grow, and increase the person's social and economic participation in real community.

Barriers to a hopeful plan can arise if key people like workers or family members hold low expectations. Sometimes barriers can arise from the complex needs that someone might have. Therefore it is essential to consciously plan to put things in place so that the good life has a better chance of happening.

How to get there (Michael Leunig)

Go to the end of the path until you get to the gate.

Go through the gate and head straight out towards the horizon.

Keep going towards the horizon.

Sit down and have a rest every now and again,

But keep on going, just keep on with it.

Keep on going as far as you can.

That's how you get there.

Questions to ask yourself

For reflection

In what ways do plans that we have developed with the person work towards their 'big dream'? In what ways do our plans keep the person stuck in a service or marginalised life?

In what ways has the person and people in their lives had a role in the planning? How could they have a greater role?

For action

Revisit a person's plan. Do the goals lead to the person's vision of a better life? Are the goals 'big enough'? Do the goals fit the person into an activity, or keep the person in 'service land' rather than community life, or do the goals help them get/maintain valued roles and more community relationships?

Good idea 8
Help people develop and hold onto their valued roles

Son, brother, husband, cousin, ex-football player, bushwalker, father of 3, TV watcher, employee, colleague, home handyman, renter, neighbour, son's footy team manager, photographer, voter, driver, grandson, son-in-law, tax payer

"In the social jungle of human existence, there is no feeling of being alive without a sense of identity." (Erik Erikson)

What is meant by 'valued roles'?

Our roles say a lot about who we are. For example, we can get a sense of someone's identity by hearing that their roles are mother, grandmother, teacher, neighbour, tenant, voter, bushwalker, TV watcher, volunteer, knitter and football fan. The roles tell us something about who she relates to, how she spends her time and what is important to her. Through her roles she has access to many of the good things of life, like respect, status, money, relationships, purpose, contribution and belonging. We choose to be in some roles; other roles are imposed, such as the role of student for a child. Some roles are removed from people, such as an older person losing the role of 'driver'.

To be in a role, we need to 'look the part' and 'act the part'. For example, for a child to be in the role of student, looking the part will involve having the school uniform and books, but also spending time in the classroom alongside other students and doing what the class is doing. To help the child 'act the part', they'll learn the school rules, be guided by teachers and school buddies, and teachers will have expectations of them academically and socially.

Why this idea is so important

Having a range of valued roles means that it is likely that the person has reasons to get up each day, has a range of relationships in their lives, and is respected. If people are disadvantaged through having an impairment and especially if they are poor, then they are often in less valued roles, like the roles of 'dependant', 'burden', 'bludger', and 'sick'. Assumptions might be made about them, such as that they can't learn or can't contribute or no one would want to freely spend their time with them. This can lead to being stereotyped and treated like 'others just like them'. Having less valued roles that have low status can lead to a lifestyle that is separate from the ordinary life paths that others value. In other words, not having a range of valued roles is likely to lead to people losing (or never gaining) their own individual

In terms of an identity,
an identity reflects an individuality,
by definition. And, if there is a
quality present,
it is recognizable
and it can be named.
If you can't name it,
it means you don't recognize it.
(Robert Fripp)

Questions to ask yourself

For reflection

Think about a person you support. What are the roles that the person is currently in? Are they roles that give purpose and respect in their life (these are probably examples of socially valued roles)? In what ways is the person learning and growing through their roles? Or are they roles that lead to marginalisation (these are probably examples of negatively valued roles)? What does all this say about the person's individual identity?

How well am I extending my thinking about what might be possible for and with the person about what their life might look like through the valued roles they could have?

For action

Name a role goal that would improve the person's life, such as 'Harry will be a full time student'; 'Mary will maintain her role of gardener'.

Good idea 9
Ensure there's a mix of community presence roles and community participation roles

What is meant by a 'a mix of community presence roles and community participation roles'?

Community Presence roles are those roles that enable an individual to be present in community life, but not actively engage in shaping that community or sharing in the relationships of that community. Examples of Community Presence roles are café goer, shopper, RSL visitor/member, movie goer and church attendee. These roles are valued roles as people without impairments are in them too, but the roles are limited in terms of helping people to belong and to contribute.

Examples of Community Participation roles include the role of employee, volunteer, good (active) neighbour, choir member, scout, hockey player, and jewellery class member. It can be seen that what these roles have in common is that generally the roles are in the areas of social, economic and educational participation, not just alongside typical citizens but also engaged with them. A Community Presence role, in contrast, is likely to be one where individuals are alongside each other, and might even have brief conversations with each other, but there is a lack of depth to the relationship and the activity. It is important to be alert that sometimes a person is described as being in a Participation role, but the reality is clouded. For example, a school student should be in a class room to the same extent as other school students, doing the same (or modified) activities in class, sports, camps and school celebrations and for homework, wearing the same uniform, mixing with peers and studying with peers. If all of those boxes can't be ticked, then it is unlikely that they will be perceived and treated as if they are in the role of

> "Everyone knows me from my [market] stall and I get to meet lots of people. I have my learner's permit and am taking driving lessons. Now I also want to go to University. Life is good." (Karli Linnkaker)

> "Our approach was not [acting] on a whim or looking for a time filling activity but [was] a very well thought through valued role to fit [our daughter] and her individual circumstance." (Meg Sweeney)

Why this idea is so important

Not all roles are equal in terms of what they bring to people. One risk for people with impairments is that their main roles are Community Presence roles, which can keep them in a marginalised situation. If the needs are for belonging and opportunities to have purpose and contribution, then Community Participation roles are more likely to bring those benefits.

Any plan should identify not only the role goals, but also the activities of the role, how the person should look to be in the role, who they will be spending time with, what skills they should learn and what behaviours are expected in the role, where the role is to be done and when. It is important to monitor each of these facets of a role so that any shortcomings in the facets do not lead to exclusion. For example, someone who attends a knitting group but who sits on the outskirts of the group does not have enough of the role facets to truly be in the group member role.

Questions to ask yourself

For reflection

In your own life, what roles bring you Community Presence, and which roles bring you Community Participation?

For action

Looking at your list of valued roles, which of the roles are likely to bring true community participation and which bring community presence?

Do this exercise about someone with an impairment. Note whether they also have negatively valued roles.

"If we lose love and self respect for each other, this is how we finally die." (Maya Angelou)

Good idea 10
Assist people to receive higher respect and status

What is meant by 'higher respect and status'?

Someone (Jackie Robinson) said, 'I'm not concerned with your liking or disliking me ... all I ask is that you respect me as a human being.' Fair enough. What about those people who are different for whatever reason and so therefore aren't well regarded. All sorts of assumptions get made about them. This idea is about helping people with impairments get the respect they deserve.

Respect and status are things that are shown to people through the ways that they are perceived and treated. People in valued roles like employee and neighbour, for example, typically get given more respect than those in negatively valued roles like 'Centrelink recipient' and 'homeless'.

Here's what we humans tend to do. It is (unfortunately) true that people make judgements about one another. So to make it more likely that we will be positively judged, it is fairly typical for people to want to be associated with people and things that are positive.

Examples of associating with positive things and people:

looking appropriate in a role e.g. looking like a beach-goer at the beach; being surrounded by people who are respected e.g. being surrounded by competent team mates in a sports team; and having possessions that 'send' good messages about someone, like a mobile phone or a skateboard for a young person.

Questions to ask yourself

For reflection

How conscious am I about the prejudice that people I support are likely to face?

Which groups in our society do I have little respect for? What can I do about this attitude?

For action

What do I need to do more of so that a person I support can have greater social status?

What do I need to do less of so that a person I support can have greater social status?

Why this idea is so important

Greater respect and status is likely to be earned if marginalised people are perceived more positively. If a person, especially someone with an impairment who has experienced rejection of any kind, receives respect then it is much easier for them to respect themselves.

It is suggested that if a paid worker is involved in the lives of people with low social status, then they have an ethical obligation to do something about how easy it is for people to be judged by how they look, or walk etc. In other words, they should try to make rejection less likely. How to do this? By making it more likely that they will be perceived favourably. In other words, help the person to pay attention to their image. The aim is to improve people's social status.

It is not suggested that a service or an individual worker can easily change the attitudes of society. It is suggested that a worker can help with 'social mobility', that is, enabling people who are the butt of prejudice to experience acceptance; enabling people who are looked down on, to have roles that gain them respect.

When a worker is faced with decision points about what is to be put in place for a person with an impairment, then the most valued option should be chosen where that is practical and feasible. For example, choose a regular club setting rather than develop a centred based group. Encourage age appropriate activities. Use an age appropriate tone of voice towards people.

We are known by the company we keep.

Examples of decisions that likely improve people's status:

If a person is to get a job as a cleaner, try and find the cleaning job that is in a valued hotel, not cleaning the local park toilets. Another example is that if an older person is to buy new clothes, then use the shop that best suits their finances; don't automatically think they need to wear second hand clothes. A further practical idea is that wherever possible, help the person look like they deserve respect, not laughter or derision. A final example is described by an older woman about how she preferred not to be 'branded' as a client/customer by the worker wearing a uniform or badge; she said, 'I'd rather be mistaken as the worker's mother than as her caree'.

Good idea 11
Create & maintain a network of family, friends and other relationships

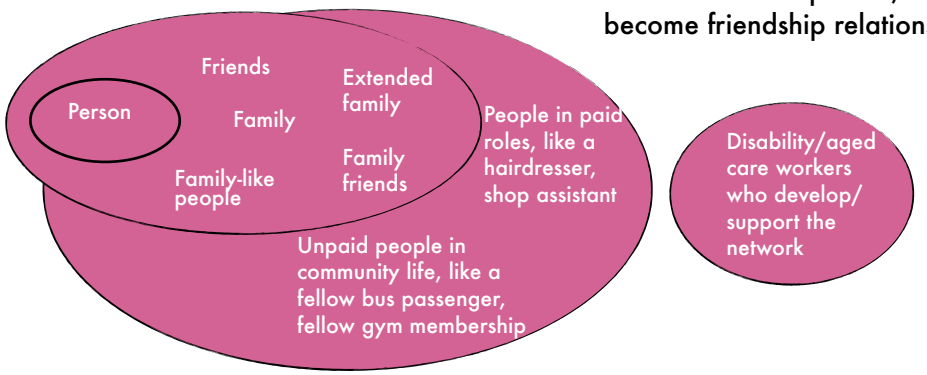
"Only those who care about you can hear you when you're quiet" (anon)

What is meant by 'a network of family, friend and other relationships''?

Part of our identity and sense of safety and security comes from knowing that we are part of a 'tribe'. A typical network of relationships consists of family, friends, acquaintances and social contacts (like the brief yet regular contact with the person at the library or fruit shop). For many people, the relationships in their lives are what give life purpose and meaning.

Closer relationships within the network are likely when 'one sees oneself in the other' because of shared interests, history, geography, values etc. In these situations, the focus is less likely to be on the impairment ie that the thing that makes people 'different', and more likely a focus on similarities like coming from the same geographical place, having shared interests, or knowing people in common.

Note that specialist paid relationships are in the circle furthest from the person, and would typically not become friendship relationships.



"I helped [a man who was marginalised] meet a woman who has now kept in touch with him for four years. They go to art shows, for walks and enjoy coffee together. They talk regularly on the phone. He describes their friendship as being 'like a sweet cup of tea'."(Neil Barringham)

Why this idea is so important

Many people with impairments unfortunately either lose or do not develop the natural extended family and friendship networks that others take for granted. Because of this, they miss out on the benefits of freely given relationships, that is, where ordinary citizens maintain an ordinary (unpaid) relationship with the person. The other impact can be that the person with an impairment seeks friends with paid workers; this can be a sign that they are hungry for freely given relationships.

Having a range of relationships across the network can do the following for and with people with impairments:

- help keep people in ordinary life through relationships with neighbours, housemates, club members, workmates and family friends
- open doors to opportunities such as being introduced to new people and being invited to have new experiences
- help keep the person safe because they are likely to be missed if they are, for example, absent from their local shops, study, interest or work group
- are best sources of knowledge for planning for a good life and for holding the dream for a positive future
- are the best safeguard for long term security, including when key family members pass away
- can help the person be less reliant on paid service workers.

Questions to ask yourself

For reflection

Do you truly believe that others could befriend this person? That they could find something attractive in their personality? That they could find a commonality in their interests?

If you don't, what beliefs are getting in the way?

For action

Put names in each of the circles for a specific person. What actions would it take for people in the connected-circles around the person to move closer to the person?

"Giving connects two people, the giver and the receiver, and this connection gives birth to a new sense of belonging." (Deepak Chopra)

Good idea 12

Facilitate belonging and contribution

"To be lonely is to feel unwanted and unloved, and therefore unloveable. Loneliness is a taste of death. No wonder some people who are desperately lonely lose themselves in mental illness or violence to forget the inner pain." (Jean Vanier)

What is meant by 'belonging and contribution'?

Belonging and contribution are experiences of the heart, not just actions. It is through our relationships and contributions that we can develop a sense of self worth, safety, security and happiness.

One definition of belonging is 'being missed when you're not there'. People might be missed for who they are in terms of their personalities and natural gifts. They might also be missed because of the tasks they do, like the work of an employee or church volunteer.

What it takes to belong and to contribute is more than simply being present in community (although that's a good start). It takes having networks of relationships beyond having a family (although that's a good start too) and paid workers. People also need opportunities for the give and take of reciprocal relationships. They are more likely to experience belonging and contribution if they are in valued roles like good neighbour, good family member, employee, member of groups, student in a class, peer, volunteer, scout, and team player. Many of these are Community Participation roles.

Why this idea is so important

It is lonely and isolating to not have friends, family or community networks. This absence of belonging impacts on one's sense of identity and worth. Yet this is the case for many people with impairments who do not have networks of relationships. The sense of belonging to a place can also be fractured for people with impairments who get moved from place to place. For example, an older person who moves to a residential away from their neighbourhood is likely to lose connections with neighbours, old friends and generic help like their GP and hairdresser.

Feelings that people can then have include feelings of exclusion and being on the margins. It is a feeling of being a 'taker' and a 'nobody'.

Questions to ask yourself

For reflection

Do you truly believe that this person with an impairment due to age or disability has the potential to contribute? Do you truly believe that this person can be loved by others for how they are and what they bring to the world? If you answered 'yes' to those questions, in what ways are you showing it? If you answered 'No', what can you do so that the answer can be 'yes'?

For action

Write down one gift or talent of a person with an impairment that you don't want to lose sight of, including during difficult times?

"Autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction and interest. It allows us to lead our own lives rather than be led along them, so that each of us can be … what he has made himself." (Ronald Dworkin)

Good idea 13

Enable real choice and control

What is meant by 'choice and control'?

'Choice and control' is about power and decision making. It is about being who you really are. It is something that ordinary citizens take for granted and cherish: we have a sense of 'crafting' our own futures by choosing our paths through life. A word of caution though … we don't actually have open choice over everything. For example, we dress according to where we are going; we generally act out of respect for others, even if we'd rather stay in our pyjamas and be rude to the neighbour.

For people with impairments, just like for those without impairments, having a sense of control over the things that matter to them is vital. This includes lifestyle decisions and decisions about their support.

Try not to think of 'choice and control' as something that services *give* to people. Think about it as not taking power away from people in the first place. Secondly, think of it as enabling people to make decisions that are connected to their real and deep identity and therefore destiny.

Where is 'true north' for the person?

And whose 'true north' is it?

Why this idea is so important

The phrase 'choice and control' is very popular today, appearing in many policies and funding guidelines. One of the reasons that it is so important is because the historical pattern for people with impairments is that as they experience dependencies, the control exerted by others (including services and families) is increased. Historically others (generally services) have made decisions about what type of support will be provided, when that support is given, where and by whom. Understandably, having decisions made by others is a way of leading to people feeling like that don't have a voice, that they aren't listened to, and lessens the likelihood of respect and trust within the relationship. These are symptoms of disempowerment.

"If people don't think they have the power to solve their problems, they won't even think about how to solve them." (Saul Alinsky)

Questions to ask yourself

For reflection

In what ways have my mindsets been limited in offering 'choice' only from what the service already delivers?

In what ways have I encouraged a person to exercise control and make choices based on what they'd really like their life to look like?

For action

What do we need to do so that we can be flexible and responsive and not expect a person to 'fit into' what we already offer?

How can we help the person to have the 'best' destiny, a destiny that is shaped by who they really are?

Good idea 14
Be mindful that someone else's home is not your workplace

What is meant by 'Home is not your workplace'?

Home is much more than the physical structure. The saying 'my home is my castle' exists for good reason. After all, it is at home that we have the most security and control. It means that those who live in that home have control over who enters, what happens there, when things happen and how it looks. Home is the central place for our closest relationships and most intimate activities. Home is the springboard for the rest of life's happenings: we go from home to work or to follow our interests. We go from home to meet people in our wider networks. Home is an expression of the personality and the histories of the people who live there: the photos, mementos, and furnishings say something about who lives there.

The following are examples of turning someone's home into a workplace: notices about worker business on cupboard doors; workers dominating the space, such as when it is the workers who decide who enters the space and what happens there; an office in a home used by people who don't live there. These things take away from a real experience of home.

"The home should be the treasure chest of living." (Le Corbusier)

Questions to ask yourself

For reflection

What does 'home' mean to you? How is it different from a workplace?

For action

List the ways you demonstrate deep respect for someone's entire home space?

List the ways that you assist someone to 'nest' at home and put down roots through being a tenant/owner, homemaker, neighbour, host etc?

Why this idea is so important

Home and one's identity are intertwined. Our homes reflect our histories, our memories, our relationships and our personalities. Karin Swift identified, based on her own experiences and observations, that 'Sadly, for many people with disabilities, home is merely a place for having their basic needs of food, shelter, clothing and support met. For some people, home is merely a vacant bed needing to be filled, or a place to receive a service.' A workplace is vastly different from 'home'.

For older people, our support should be such that the choice is not between increased vulnerability at home and institutionalisation, but rather to continue to benefit from what is important about 'home'.

It is therefore vital that workers, when working in people's homes, assist the individual(s) to truly make and experience their own 'home'. This means respecting the physical space as someone's personal property. It means enabling the person to create their home as an expression of themselves. It means deeply respecting the private spaces of people's home, and of the important routines that are part of the individual's lifestyle and culture. It means not taking over the home simply because a worker happens to be paid to be there.

"A man travels the world over in search of what he needs and returns home to find it."

(George A. Moore)

Good idea 15

Keep people safe

What is meant by 'keep people safe'?

Two ideas are very effective and respectful ways of keeping people safe.

Firstly, it is people who keep people safe. It is ordinary citizens who step forward as allies and friends who keep people with disabilities safe. Like the deli worker who notices the absence of the person who comes to his shop very regularly and so makes a phone call to find them. Or the neighbour who sits with a person after an accident until family and workers arrive. Or the club member who drives the person home rather than leave them vulnerable with an unknown taxi driver. Or the fellow bowling club member who stands alongside the person when they challenge a dishonest landlord.

These true examples illustrate that there are 'sweet spots' in community life where good people will step forward. This is important in creating the sorts of communities that are good for all people. It also builds people's sense of personal responsibility, self esteem and independence.

The other thing that helps to keep people safe is helping them to build their skills, such as skills like being able to use a phone, say how they're feeling, spend alone time safely, and develop the social skills to have relationships with neighbours, family friends, club members and shop keepers.

In contrast, a common belief is that it is paid workers who protect vulnerable people from mean or unscrupulous people in the community. It is also thought that policies and rules provide the guidelines to workers who then know how to avoid harm. It is also often thought that being separate from ordinary community keeps vulnerable people safe. These beliefs and practices, while they have grains of truth, are insufficient. Also, unfortunately, these responses can lead people into service-based lives rather than culturally typical lives.

Why this idea is so important

It is fair to acknowledge that many people with impairments live with vulnerabilities to physical, emotional and financial abuse. They are also vulnerable to making mistakes that might not be in their best interests. It is important not to respond by 'wrapping people in cotton wool'. Similarly it is important not to respond with lots of rules that actually limit the opportunities for learning and for ordinary community members to step in.

Ideally, whatever ways that are used to 'keep people safe' should result in a person with an impairment having stronger ties to a network of relationships and a sense of learning to be independent.

"An important part of planning for and safeguarding our family member with disability will always include involving others in their lives. When the people who are involved have a clear understanding of our vision for our family member and their vision for themselves, then the involvement [of others] is more likely to reflect our hopes and wishes." (Pave the Way)

Questions to ask yourself

For reflection

In what ways have I been overprotective? In what ways have I been under-protective and which has led to some type of harm (including harm to someone's dignity)?

In what ways have I helped someone be more safe by bringing people into the person's life and helping the person be more independent?

For action

Think of a person with an impairment you know well. Write down three things that would keep them more safe, and that doesn't involve 'wrapping them in cotton wool'?

What is an example of someone learning a new skill or using existing skills that would help keep them safe?