



PAVE THE WAY

vision to action through planning

Developing and Maintaining a Support Circle

A resource for people with disabilities and their families

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Ideas and
strategies

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The National Disability Insurance Scheme and Participant Readiness.

The National Disability Insurance Scheme (NDIS) is a new Federal system for ensuring people with disability have the support they require to engage more fully in social and economic life.

The scheme will provide eligible participants with reasonable and necessary supports and change the way disability services are delivered to ensure participants have more choice and control over the supports they receive.

The NDIS is in its early stages and there are still many uncertainties about how the system will work. However, information coming from the NDIS trial sites in parts of Australia over the past year, is that people with disabilities, their families and carers are able to make the most of the scheme when they do some whole-of-life pre-planning with their own family and networks ahead of their meeting with the National Disability Insurance Agency (NDIA), the name given to the organisation responsible for delivering the NDIS.

Under the NDIS, participants will be encouraged to think about what will make a good life for you and look at both the formal and informal supports that will help you to achieve the desired future you are planning for.

While the NDIS is a welcome reform for people with disabilities and their families and carers, the key message remains: although the role of services and funding are important in ensuring the quality of your good life, ultimately it is people who keep you safe.

Support circles can play a key role in assisting people with disability and their family/carers with informal decision making, advocacy and planning. Support circles are also an effective strategy to ensure there are people in your life who are not paid to be there.

This document provides an overview of the theory and practice of support circles as well as some practical considerations in developing and maintaining a support circle.

Thinking about the purpose of your support circle

The concept of support circles is not a new one. We all need support from each other from time-to-time. For many people this is a vital part of what makes up our community. The creation of intentional support circles for people with disabilities has its origins in Canada in the early 1980s. Over this 30 year period many people with disabilities, their families or carers have invited others to form a support circle as just one strategy to safeguard them now and into the future.

For the many people with disabilities and families that Pave the Way has worked with, a support circle has been one way of gathering together on a regular basis, a group of people who are committed to you, to support you in your decision-making and planning for a good and safe life for now and the future. With the NDIS approaching, a support circle may assist you and your family to think about what supports you have in place now and what others you will need in the future and how best to manage these supports.

Deliberately involving others is useful, because while it might be important to have funding and services and legal things such as wills and trusts in place, at the end of the day it is our friends and families who keep us safe.

If *'people keep people safe'* then people who love you and are committed to you will need a way to be involved with you and a support circle is one way of achieving this. The role of circle members is not to replace your family but to support you and your family's efforts to continue to build a life for you which will ensure that you remain happy and safe now and into the future.

When a person decides to develop a support circle, it is important to consider what the purpose of the circle will be. The clearer you are about its purpose, the more likely it is that the support circle will function well. In the context of the NDIS a support circle may assist you to:

- Safeguard what is important in your life when talking to an NDIS Planner
- Assist in making critical decisions around who should and should not provide support and how this support should be managed
- Continue to grow your vision of a good life into the future

Facilitation

Support circles can function well when someone is responsible for facilitating the meetings.

A good facilitator will be someone who values you and your family and respects your vision for your future. While this might make it more tempting for close family members to facilitate the meetings themselves, it may not be a good idea as it is important that your family has the freedom to participate in the meetings, if appropriate and not get caught up worrying too much about the process. Also, meeting with a group of people around some sensitive issues such as hopes and fears, requires someone who can listen clearly and lend support to you and your family if the discussion becomes difficult or sensitive.

Facilitation means: *to make easy or to help progress*, which describes the facilitator's role well. A facilitator can assist the group have a focused and purposeful conversation and ensure that everyone has the opportunity to participate in a safe and respectful way.

Some of the key values, skills and qualities for a facilitator might include:

Values

- A belief that people with disabilities have the right to live a life which is meaningful to them and that reflects their hopes and dreams. An ability to speak about your hopes, dreams and gifts will be important when talking to an NDIS planner.
- A belief in the value of give-and-take in relationships
- A belief that we all have gifts

Skills and qualities

- An ability to seek clarity and shared understanding among the group
- An ability to involve all circle members in discussions rather than being the expert with all of the answers
- An ability to draw out a response from the participants
- An ability to move a group's ideas into actions
- An ability to listen deeply

Some of the key facilitation responsibilities

- To assist you and your family organise the meetings, which includes assisting you to set the agenda prior to circle meetings
- To help circle members share their ideas and contribute to the discussion
- To keep things moving forward by listening, questioning, reflecting back and clarifying
- To lead the group through discussion, brain storming, problem solving and hope building
- To assist all involved with understanding and respecting your authority
- To ensure that you have a voice
- To ensure that someone is keeping notes

How and where to find a circle facilitator

Finding a suitable person to facilitate circle meetings may be as simple as looking within the circle group, or it can be complex, as it may be necessary to look beyond the group to yours/ or your family's networks or to people from the circle's networks.

The following ways of finding a facilitator or managing the circle meeting process show the many approaches and depend on each person's needs, hopes and resources.

Circle group

Someone from within the group may be competent and confident to take on the facilitator role. Some groups rotate the role among two or more members. With this model, Pave the Way can provide some initial orientation and ongoing support to the facilitator if they wish.

Your family or the circle's networks

Someone from your local community, a neighbour, a church or club member, or a co-worker for example, may enjoy the opportunity to facilitate your support circle. A circle member or friend might be happy to

approach someone on your behalf.

<http://www.pavetheway.org.au/home/stories-pave.php>.

Professional facilitator

Some people may prefer to have someone with extensive disability or community work knowledge or previous facilitation skills to facilitate their circle meetings. Often professional or consultant facilitators require payment as facilitation is their job and their source of income. Some people pay a facilitator from some funds or savings, or their Disability Support Pension for example.

Facilitation from any chair

It can be a daunting task for someone to take on the facilitator role without any previous experience, if all the responsibility for the meetings rests with just that one person. So while it is important that someone (the facilitator) assists the group to have a productive conversation, it's a good idea that each circle member contributes to the discussion and understands the circle process.

Often the facilitator is wrongly seen as the 'leader' of the group and therefore, the one who raises all the questions or provides all the answers. However, the facilitator's role is to encourage the group to do these things in a focused, forward-moving and respectful manner. A meaningful and productive discussion requires a group effort and each circle member can contribute to the whole.

Payment of a facilitator

Whether the facilitator comes from within the circle group or from someone's networks a decision about payment will need to be made. For some people the payment of a facilitator or the presence of a paid person in the circle seems incongruent with the concept of gathering people together based on love and commitment to you.

Others prefer that the facilitator comes from outside their circle group, as they are looking for a more neutral person to take on the role. Some people also worry about imposing on someone's time and therefore may be more comfortable with paying a facilitator.

Ultimately it is up to you and/ or your family whether the facilitator role is paid or unpaid, developed from the group or rests solely with one person. The important thing is that you and your family are comfortable with whoever takes on the facilitator role.

How circle members can be involved with the process of the circle meetings.

While it is important that there is someone responsible for the facilitation of circle meetings, it is equally important that all circle members come to understand and get involved with, the circle process. In doing so, circle members can act together to safeguard the circle by ensuring that all the facilitation does not rest with just one person. Understanding the circle process will also assist with the function of the group as a whole.

A way to increase this understanding is to assist the group to become familiar with various aspects of the circle process and to ask them to nominate areas that they would like to be responsible for. Being responsible for one or two aspects of the role is also an effective way of getting circle members engaged in the meetings.

Benefits:

- Each person has a sense of ownership and responsibility for the process
- Circle members may come to understand the circle process more fully
- The facilitator is free to focus on facilitating the meeting
- Bringing new people into the circle is in the back of your, your family and circle members' minds

Circle members bring with them particular gifts and strengths and this is often reflected in the way they participate in meetings. It may be because of a particular gift or strength that you considered inviting someone to the circle in the first place. Certain personalities will suit certain roles. Some people, for example, are organisers and want things to have happened 'yesterday'. They might, unsurprisingly, see opportunities that arise in a discussion that could move a very good idea into a very do-able action - NOW.

Someone else may have always been a strong advocate for you. They may be the one who can be conscious of the need to bring the discussion back to you and seek your opinion and decision about it. This person would also be a good person to take with you to a conversation with an NDIS planner.

Some people are dreamers and can become frustrated with the doers and practical ones; they might bring a more creative solution to a complex problem or a different angle to an idea.

Circle members can be encouraged to think of their particular strengths and find a role in the process that suits them best.

Some of the roles might include:

- Assisting you or your family to set the agenda
- Assisting the group to set circle meeting dates
- Note taking (or assisting the note-taker document the discussion).
- Time keeping (most people try to keep the meetings to a maximum of 2 hours and it does help if someone is keeping an eye on the time).
- Keeper of the vision (some people find it useful for someone to keep the vision in mind and remind the group of the vision when important decisions are being made).
- Ensuring you have a voice and that your wishes are respected.
- Assisting to keep the conversation focused and moving forward.
- Helping to bring side conversations back to the group.
- Advocating for you or your family.
- Bringing an 'ordinary antenna' rather than a disability orientation (circle members can bring their own experiences and stories about the topic being discussed to enrich the conversation). It is a great idea to invite people who do not come from a disability perspective. School friends without disabilities or friends of siblings can be a great source, as they have often grown up with you and have probably spent time with you separate from your parents.
- Supporting the note-taker document information accurately, or by summarising a lengthy discussion.
- Having appropriate and respectful interaction with you.
- Inviting another person with disability or a parent of someone with disability to be involved with your support circle (they may bring empathy, advocacy and disability sector and lived experience to the discussion that friends or extended family may have limited knowledge of initially).

Note Taking

Many circle groups find taking notes of the circle meeting discussion helpful. Notes can assist the group stay on track and focused, and can be a good way of seeing how far the group has come in achieving your vision.

If you decide to take notes then it's important to work out what you do and do not want to include in the notes. What kind of detail or information needs to be recorded? What kind of language would be used ~ formal or informal? Who will receive the notes? Where will they be kept?

Some people send notes out to all of the circle members, some to extended members of your network, while others keep them in a central place (usually the family home or the person's home) rather than send them out.

Some people include their vision on the header of all of the notes to remind all involved of the main purpose of getting together as a circle. Some people capture a great amount of detail while others will use dot points to serve as a prompt only.

The important point is, there is no recipe and the best way to organise the circle meetings is in a way that reflects your hopes and expectations, and the values you want the circle of support to have.

Some tips that families have suggested for effective note taking:

- Listen carefully.
- The note-taker could ask the group or main speaker how they want the main points of a long discussion written down.
- Using a laptop, rather than pen and paper during meetings can save time as you avoid needing to rewrite notes.
- Encourage all the participants to be aware of contributing to the notes by helping the note-taker with wording or context, for example.
- Type notes soon after the meeting so you can seek clarity from others while it's still fresh for them.
- Send the notes out in a reasonable time frame.

- Have rules around confidentiality (not letting people outside the circle see the notes).
- To save time and help with the meeting process, you could use a template for the notes. The group could work out the best format to use for capturing the discussion.

Examples of meeting structure and note taking templates

The following templates are just headings to help you think about introducing some structure to your circle meetings. Having some structure can help the group stay focused and on task and helps to build a routine that can assist all circle members understand the circle process more easily. You may want to have standing or regular agenda items that you discuss every meeting, for example, hopes, dreams, goals, planning for the NDIS.

The following is an example of a more formal template:

Date
Present
Apologies
Business arising from last meeting
Current Agenda
Planning item and actions
Next meeting date/s
Food arrangements (if any)

Or a less formal template:

Date
Who is here
Who couldn't make it
Round Robin
What's been happening since last meeting
Today's discussion
Next meeting date and food

Trouble shooting ideas or common stumbling blocks

While many people have appreciated and enjoyed the experience of a support circle, the journey has not been without its challenges and difficulties. Over time some people have shared their experiences and some of the challenges that have arisen. The following points have been gathered through feedback from people with disabilities and their families.

A successful circle generally depends on:

- A shared understanding of you – the person who is the focus of the meetings.
- A shared understanding of your vision for your life.
- A shared understanding of your family's vision for your life.
- A shared understanding of the circle meeting purpose and processes (including what good facilitation is and circle members roles etc)
- Adequate membership.
- No one, single circle member dominating the process or discussions.
- A willingness of circle members to take on difficult challenges.
- You and your family, if appropriate, having authority and ownership.

Working out how to learn more about the above points would be time well spent and may prevent some of the more common stumbling blocks.

Facilitation

Sometimes finding a suitable facilitator can be the lengthiest part of getting a circle going. Some people have decided that rather than delay or stall the enthusiasm that they have gathered, they would begin to meet without a facilitator and some of the following ideas are things the group can focus on in the meantime:

- Invite a guest speaker to attend a meeting to share their story (another individual/family who has a support circle, or a family whose son/daughter has achieved a similar goal to the one that you hope to achieve ~ moving into a home of your own, finding meaningful employment etc).
- Work together to gather important information about you. This information might include for example: What you do during the day; the key people in your life; your hopes and dreams; important medical information. This is very useful to do in preparation for the NDIS. There are a number of resources available to assist people with getting this information together including, *A Document of Personal Information*, which has been developed by Pave the Way.
- Circle members could share the facilitation role until one person can take on responsibility for the role.
- The group could get together socially rather than hold formal meetings, or alternate social gatherings with formal meetings. This might be a good opportunity for circle members to get to know you and/or one another much better also.
- Meet less frequently, although meeting regularly is a good idea. Most circle groups meet 4-8 weekly and this seems important for maintaining the energy of the group. However, if it is proving too difficult to sustain the group without a facilitator then meeting a little less often is okay - but the circle should still focus on getting to know you better (if needed) and gathering important information and looking for a facilitator.
- A facilitated planning session can provide direction for circle meetings and make meeting together possible without a facilitator.

- Continue to discuss ways to find a facilitator with the group and others if necessary.

Disability knowledge and perspective

Some people find it is beneficial if circle members know more about disability related issues (such as the NDIS) and they have benefitted from the group growing in their understanding of these issues. To achieve this you could:

- Invite another person who has a disability or a family who has a family member with disability to a circle meeting to talk about a particular experience/aspect.
- Invite a guest speaker to a circle meeting to talk about a disability related topic. This might be a service provider, a speech or occupational therapist for example.
- Share articles, books or DVDs for circle members to read/view and reflect on together at circle meetings
- Employ a facilitator who has the necessary disability experience and background.

Setting dates

When it seems difficult to come up with a date for a circle meeting that suits everyone:

- Establish with the group how often circle meetings should be (it is important to be realistic about this) and an agreed suitable time for circle meetings.
- Find a time that suits most people most of the time, set a routine early and stick to it.
- Encourage everyone to bring diaries to each meeting so that dates can be set in advance and people are able to plan around them if possible.
- Try not to change dates too often to meet everyone's needs. This can affect the success of the circle very quickly and also puts pressure on anyone who is unable to make a particular meeting.

When it is difficult to maintain the circle's energy or focus

From time to time all circle groups seem to struggle with maintaining the energy or focus of the meetings. This may be quite natural but it is important not to lose energy to the point of becoming unworkable.

Some remedies for this might include:

- Ensuring the group understands your vision, as your vision should provide the focus of the meetings.
- Revisiting your vision to create ideas and goals on which to focus. Preparing for the NDIS is useful as it is starting in Queensland soon.
- Preparing an agenda for the meetings.
- Reflecting on how far the group has come and on some of its achievements.
- Organising for a facilitated planning session or review to set new goals and direction.
- Regularly reviewing the purpose of the circle meetings and working out if that purpose is still current or whether it has changed.

When circle members are nervous about acting on their own suggestions

This is a common area of frustration for people, so it helps if time is spent on developing a shared understanding at the beginning, of what circle members may be involved with regarding suggestions that are given.

- Be clear about what you have asked people to contribute and the expectations of their roles.
- Assign someone in the group to ask *'who else, other than you or your family has a potential role, interest or responsibility here?'*

Dealing with negativity or different views

For instance, some people have invited friends they find out do not share their vision for a good life, or who may be negative about what you are trying to achieve.

- Perhaps have a core group with whom you get together frequently and focus on your vision and planning and another group that gets together less frequently and on a more social basis.
- When possible, turn any negative views or comments into a positive statement (i.e. the view that, 'Janet is so controlling', can also be translated as 'like all of us Janet likes to make her own decisions about things that are important to her').

Some other considerations

- If possible, try to find a way that circle members can get to know you well (ask the group to suggest ways they could and would like to get to know you better)
- Work out whether you want to involve your siblings (now or later) or not. This is an entirely personal decision and should not be influenced by the opinions or agendas of others. Only you and/or your family can know when and if it is appropriate to involve siblings.
- Support circles can be a lot of work. Circle members can contribute some great ideas, but not necessarily take on any responsibility for their own ideas. This often means you or your family has more work to do. Sometimes this work is your responsibility or that of your family, but it might also be an opportunity to look beyond yourself and ask others for help. Some people are all too happy to help; they may just be waiting to be asked.
- The number of circle members does not matter as much as who is involved. Some people have found larger groups too difficult to manage; while for others it is a case of the more the merrier. The important point is that you are comfortable with all of the people you involve.
- It is important for all circle members not to assume that the answers to any difficulties only rest with a facilitator, but with the whole group, or others who may not even be present.
- Speaking with other individuals/families who also have a support circle can be a huge source of support, information and ideas sharing about any stumbling blocks you experience.

Suggested further reading, links and resources

Articles and Stories

These articles and stories are available on Pave the Way's website at www.pavetheway.org.au or can be mailed by request.

- *Building Intentional Lifelong Safeguards*
<https://www.pavetheway.org.au/sites/pavetheway.org.au/files/documents/Building%20Intentional%20%20Lifelong%20Safeguards%20Article%20January%202010.pdf>
- *Daring to Dream* ~ This is a story about one family's experience of establishing a support circle.
<https://www.pavetheway.org.au/daring-dream>
- *Finding a Facilitator* ~ This story tells of one family's journey to find a facilitator for their support circle meetings.
<https://www.pavetheway.org.au/finding-facilitator>
- *Sarah's Support Circle, a regional story* ~ This story is about one family's creative response to developing a support circle when most of the circle members live at least 400 km away.
<https://www.pavetheway.org.au/sarahs-support-circle-regional-story>
- *Facilitating Support Circles: An overview*
<https://www.pavetheway.org.au/sites/pavetheway.org.au/files/documents/Facilitation%20%20ideas%20and%20strategies%20July%202014.pdf>

CRU Newsletter

Crucial Times March 2007 Issue 38 ~ the articles in this edition of CRUcial times are focused on support circles

<http://cru.org.au/wp-content/uploads/2013/03/CRUcial-Times-38-Mar-2007.pdf>

Books

The following books can be purchased from the links provided. If you are unable to purchase these online, contact Pave the Way and we may be able to assist.

A Good Life – for you and your relative with a disability. Etmanski, AI PLAN Canada (2004).

- A very readable and practical book dealing with the fundamental issues of what it takes to imagine and plan for a good life for our family members with a disability. Includes information about building relationships, developing long-term plans, and ensuring that your plans are secure.

This book can be ordered through Community Resource Unit Inc. (CRU) <http://cru.org.au/shop/> or <http://store.planinstitute.ca/collections/books>

We Come Bearing Gifts, Klees, Janet (1996).

- The story of a small group of ten Canadian families who formed the Deohaeko Support Network in order to achieve their vision of a positive future for their sons and daughters who have a disability. One aspect of their vision has involved developing a support circle as part of their own support solution.

This book can be ordered through CRU <http://cru.org.au/shop/>

Our Presence Has Roots, Klees, Janet (2005).

- The ongoing story of the Deohaeko Support Network.

This book can be ordered through CRU <http://cru.org.au/shop/>

Stronger Together: Ideas, reflections and suggestions about networks of support. Kappel, Bruce (1998).

- This is a practical resource that provides a compilation of ideas for building and maintaining a network of support.

The Company of Others ~ Stories of Belonging, Shields, Sandra and Champion, David (2005).

These notes are intended as a guide only. While all care has been taken to ensure accuracy, further information should be sought before any planning decisions are made. For further information or to talk about these issues, please contact Pave the Way on 07 3291 5800 or pavetheway@pavetheway.org.au

- A photographic book that tells the stories of five people who are surrounded by social 'circles' – friends and family whose respect, encouragement and love give them a sense of belonging in the world.

This book can be ordered through PLAN Canada
<http://store.planinstitute.ca/>

DVDs

Circles of Support

- This DVD tells the story of a two families in South Australia and their support circle journey. Community Living Project (2007).

For more information contact CLP on (08) 8384 7866 or visit their website at www.clp-sa.org.au

The Ties that Bind

- The story of a young man and his personal network (2005).

This DVD can be ordered through PLAN Canada
<http://store.planinstitute.ca/collections/books>

Websites

Community Works www.communityworks.info

The website of David and Faye Wetherow includes a range of articles around what it takes for a person with a disability to live an ordinary life in the community.

Inclusion Network www.inclusion.com

The Inclusion Network website features articles about planning and circles of support.

Microboards

Microboards are a similar concept to support circles but differ in some regards. Originally developed in Canada by the Vela Microboard Association, microboards involve small groups of people, usually committed family and friends, who come together on a regular basis to

provide support for a particular person. For more information visit the Vela Microboard Australia's website. www.microboard.org.au.

Another website that features articles about the microboard concept can be found at: www.communityworks.info

Pave the Way

www.pavetheway.org.au

The Pave the Way website includes a number of articles and stories about support circles. The website is often updated with new information.

Plan Canada

www.plan.ca

Planned Lifetime Advocacy Network (PLAN) is a non-profit organisation, established in 1989 by and for families committed to future planning and securing a good life for their relative with a disability.

Resourcing Families

<http://www.resourcingfamilies.org.au/building-support-networks/>

Resourcing Families provides information and ideas for families, friends and allies of people with disability so that they can have knowledge, skills, confidence and networks to plan a good life for and with a person with disability.

You will find stories from families, video clips, 'how to' documents, fact sheets, articles, policy documents and links to resources that will help you to both plan and implement ideas.