SETTING UP
A NOT-FOR-PROFIT
AND RAISING FUNDS

SECTION FIVE
THE CARER PEER SUPPORT GROUP
FACILITATORS GUIDE

CONTENTS

REGISTERING AND INCORPORATING A GROUP

At the start, your carer peer support group may be fairly informal but grow and develop into a more formalised structure over time.

Whatever way your carer peer support group begins you may at some point want to raise funds to progress the group or for a specific project.

To be eligible to apply to some bodies for funding you may need to be a registered group. It may also help to open a bank account in the group's name.

Be clear about the purpose of your group and how it would benefit by becoming a registered association. Your carer peer support group, legally and financially, would be classified as a not-for-profit organisation.

Auspiced and Affiliated Groups

If financial activities are not regular or you remain small with limited financial means or activity, you may be able to become auspiced by, or an affiliate of, an existing established organisation such as a community health centre or neighbourhood house.

Advantages of these arrangements may be:

- use of meeting rooms with public liability insurance cover
- use of equipment
- use of kitchen facilities for tea, coffee, etc
- provision of tea/coffee
- assistance with funding applications under an auspicing organisation.

Registered Groups

There are generally two types of registered not-for-profit associations. They are:

Unincorporated associations

- An unincorporated association is a group of people who agree to act together as an organisation and form an association. The group can remain informal and its members make their own rules on how the group is managed. The rules may also be referred to as a constitution. The individual members are personally responsible for the association's activities.

- An unincorporated association is not recognised as a separate legal entity to the members associated with it

- An unincorporated association is an entity under tax law and treated as a company for income tax purposes.

Incorporated associations

- An incorporated association is a legal entity separate from its individual members. Associations are incorporated under the state or territory legislation in which they operate.

- An incorporated association can continue regardless of changes to membership.

- Incorporated associations have a number of responsibilities such as financial record keeping and reporting, following constitutional rules and holding annual general meetings.

- Financial protection is provided to individuals by limiting personal liability to the organisation, not individuals, by being able to take out insurance.

To become an incorporated association in Victoria

You must register with Consumer Affairs Victoria.

All the details are available at **www.consumer.vic.gov.au/clubs-and-fundraising**.

Alternatively, you can phone 1300 55 81 81.

If you want to operate beyond Victoria

You will need to register with the Australian Securities and Investments Commission (ASIC).

For full details visit **www.carersvic.com.au/asic**

Starting a Not-For-Profit Organisation

To access the most comprehensive government information on establishing not-for-profit organisations visit the following websites:

- Australian Taxation Office **www.ato.gov.au/Non-profit**

- the Australian Charities and Not-for-profits Commission **www.acnc.gov.au**

- the Australian Securities and Investments Commission **www.asic.gov.au**

Justice Connect **www.justiceconnect.org.au** is also a useful resource and provides a clear explanation of incorporation options and processes in Victoria. Their not-for-profit law service provides free and low-cost legal resources, training and advice to community organisations.

Consult an accountant or lawyer before making any decisions.

PRIOR TO REGISTERING FOR INCORPORATION

To help the group be clear about the purpose and how the group will be run, you should establish the boundaries and objectives of the group. You will need to have prepared this prior to writing the association's constitution. This should be documented in a Terms of Reference.

TERMS OF REFERENCE

A "Terms of Reference" (TOR) is simply a description of the aims and structure of your carer peer support group. The aims and structure of the group will depend on what the people in the group want to get out of it. What are the expectations of the group? Do members want an informal group that meets indefinitely for a cup of tea and a chat? Or do they want something more formal with structured discussions and regular guest speakers?

It is a good idea to discuss everyone's ideas and expectations at the first meeting. You may like to brainstorm, using a white board or go around the circle asking what everybody would like to get out of the carer peer support group.

Your TOR should address:

- vision and objectives of the carer peer support group (i.e. what you want to achieve)
- members, roles and responsibilities (i.e. who will take part in it)
- resources, financial plan (i.e. how it will be financed)
- relationships with other bodies/associations/community.

At the end of your discussion it is important to agree upon the TOR and document them. Each member of the carer peer support group should be provided with a copy.

COMMITTEE ROLES

Some carer peer support groups prefer to keep their roles and committees very informal, while other carer support groups like to be more formal and assign roles or committees for the group.

At your first meeting you should discuss each role and decide who is the best person for these roles. Some roles may be shared if this is more suitable for members. It is ideal to have more than one Facilitator or Coordinator; for example to share the task and to help the group dynamics.

Below is a list of possible roles

Facilitator or Coordinator

- Runs and leads the meeting.
- The contact person for the carer peer support group for telephone enquiries and mail.
- Informs relevant organisations of the aims of the carer peer support group and asks for their support.

Secretary

- Looks after paperwork, maintains membership details, types up meeting minutes, sends out meeting reminders etc.

Treasurer

- Pays the bills, receives incoming money, keeps accurate financial records.

Communications or Publicity Officer

- Promotes the group through media releases, group newsletter, emails, flyers, social media.

General committee members

- Help with decision making and other tasks as needed.

FUNDRAISING

In Victoria individuals and organisations do not need to register to fundraise if less than $10,000 gross in a financial year is raised using only unpaid volunteers and meet other exempt requirements. However, there are strict requirements if you expect your event or activities will exceed that amount.

Please check with Consumer Affairs Victoria for details before starting any fundraising **www.carersvic.com.au/consumervic** or phone 1300 55 81 81.

DONATIONS

Some businesses or individuals may wish to make a donation to your carer peer support group. They may also request a tax-deductible receipt for their donation. To be able to provide them with such a receipt your carer peer support group will have to become a registered 'Deductible Gift Recipient' (DGR).

This means that your group will need to be registered with the Australian Charities and Not-for-profits Commission (ACNC).

See their website **www.acnc.gov.au** or phone 13 22 62 for more detail.

Please note Government and legal requirements can change from time to time. Check directly with these bodies when you are setting up or undertaking these activities for exactly what is required at the time.

SPONSORSHIP

Seeking sponsorship from local businesses or other groups is another way of funding of your group.

For example:

- local businesses such as the local supermarket
- local Lions Club or Rotary Club
- RSL or CWA groups
- local council
- cultural groups.

This sponsorship could be 'in-kind' or practical rather than monetary. For example, use of the Senior Citizens club room for holding your meetings, or the Lions Club holding a sausage sizzle at an event you hold.

REGISTERING FOR AN AUSTRALIAN BUSINESS NUMBER (ABN)

An ABN is a unique number which identifies your organisation with the Australian Taxation Office (ATO) and other government agencies. You do not need to have an ABN, but it can be helpful for reasons including:

- registering your group's name so no other group can use it

- it is needed for applying to be a Deductible Gift Recipient

- dealing with invoices from suppliers

- claiming GST

- can be helpful if setting up a bank account for the group

- applying for grants.

If you decide to register your carer peer support group for an ABN there are several steps to follow all of which can be done online:

- Check whether the name of your group is available on ABN LookUp at **www.abr.business.gov.au**

- Register your organisation with the Australian Business Register at **www.carersvic.com.au/abrgov** or phone 13 92 26.

- You will also need a tax file number (TFN). You can apply for an ABN and a TFN at the same time.

- Visit the ATO website at **www.carersvic.com.au/ato** for full details as tax may be payable.

For more information about an ABN, GST registration and taxation issues talk to an accountant or phone the Australian Taxation Office on 13 28 66.

INSURANCE

Your carer peer support group's insurance requirements depend on how your carer peer support group is structured, where you meet and if you are affiliated with any other organisations.

In Victoria all incorporated associations must indemnify its office holders for liabilities they incur in good faith while performing their duties. This means that any expenses the office holder incurs on behalf of the association must be reimbursed to them.

Incorporated groups also need to consider the following.

The group should take out insurance which is tailored for not-for-profits. Make sure it covers all 'directors and officers' to ensure personal coverage for members.

The main types of insurance are

Public liability insurance

This type of insurance protects your carer support group against paying compensation to a third party who suffers loss, injury or property damage as a result of a mistake or negligence by your group or by one of your members.

Personal accident insurance

This type of insurance covers the carer support group against costs that may arise from a member being injured through an accident that occurred as a result of, or while, attending your meeting or activity. Sometimes known as Volunteer Insurance.

Directors and officers insurance or association's liability

This policy covers the personal liability of carer support group members if they make an organisational decision that causes such acts as causing financial loss to another person or to the group, asks someone to undertake a dangerous activity which results in loss, or are negligent. If you have public liability insurance you may not need this type of insurance.

Being auspiced by or affiliated with another organisation their insurance may cover your meeting place, and activities needs. If considering these arrangements be sure to ask about insurance coverage.

TIP When considering your insurance needs check with Consumer Affairs Victoria and insurance brokers who specialize in insuring not-for-profit organisations before making any decisions.

See Justice Connect **www.nfplaw.org.au** for more detail on Insurance and Risk Management for Community Organisations.

The information contained in this document is a general guide only and is not legal or financial advice. For all financial and legal matters seek independent professional advice.

Carers Victoria thanks Carers NSW for permission to use information from the 2010 publication *Setting up a Carer Support Group.*

EVIDENCE TO SUPPORT A GRANT APPLICATION

In applying for grants you will generally require a strong evidence base supporting the benefits of peer support and how the funding will be used to enhance the outcome for the group and community.

To ensure you back up the evidence it is important to include the source of the research.

This section provides some examples of contemporary research and data which corroborate the benefits of peer support, and can be included in applications for funding, if needed.

In disability peer support for parents and carers, there is evidence that focusing on the positive aspects of parenting a child with disability with someone who has 'been there' was helpful in reducing stress (Bray et al, 2017).

Bray L et al, 2017. Parent-to-parent peer support for parents of children with a disability: A mixed method study. Patient Education and Counseling. Volume 100, Issue 8, p.1537-1543. Available at www.carersvic.com.au/sciencedirect

One important approach to supporting families is through peer support. The value of unique shared experience has been widely discussed and recognized as an important complement to other professional support services. (e.g. Ainbinder et al., 1998; Dennis, 2003).

Refs: Ainbinder, J.G., Blanchard, L.W., Singer, G.H., Sullivan, M.E., Powers, L.K., Marquis, J.G., Santelli, B., & the Consortium to Evaluate Parent to Parent. (1998). A qualitative study of parent to parent support for parents of children with special needs. Journal of Pediatric Psychology, 23, 99-109

Dennis C, 2003. Peer support within a health care context: a concept analysis. International journal of nursing studies, Volume 40, Issue 3, Pages 321–332. Available at www.carersvic.com.au/nursing

Sartore G et al (2013) also highlights the importance of peer support for parents of children with complex needs that may be experiencing or fearing stigma, and therefore avoiding contact with others.

Sartore G et al, 2013. Peer support interventions for parents and carers of children with complex needs (Protocol). Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD010618. DOI: 10.1002/14651858. Available at www.carersvic.com.au/cochranelibrary

A literature review undertaken by Canadian researchers (Leung et al 2002) revealed that although past research findings are limited due to the lack of rigor in their methodologies, significant gains have been described by participants of groups offering peer support in areas of:

- self-esteem

- better decision-making skills

- improved social functioning

- decreased psychiatric symptoms (i.e. decreased rates or lengths of hospitalization)

- lower rates of isolation, larger social networks, increased support seeking

- greater pursuit of educational goals and employment.
  (Davidson et al, 1999; Humphreys & Rappaport, 1994; Froland et al, 2000).

Davidson, L, Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. (1999). Peer support among individuals with severe mental illness: A review of the evidence. Clinical Psychology: Science and Practice, 6(2), 165-187.

Humphreys, K. & Rappaport, J. (1994). Researching self-help/ mutual aid groups and organizations: Many roads, one journey. Applied & Preventative Psychology, 3: 217-231.

Froland, C., Brodsky, G., Olson, M., & Stewart, L. (2000). Social support and social adjustment: Implications for mental health professionals. Community Mental Health Journal, 36(1), 61-75.

The Peers for Progress Development Guideline, available at www.peersforprogress.org, provides up-to-date evidence-based guidance with respect to peer support program development, implementation and evaluation.

A systematic review by Shilling et al (2013) on the benefits of peer support for parents of children with chronic disabling conditions identified four consistent themes, which may provide an example of key functions that have supported disability peer support programs:

- social identity

- learning from the experiences of others

- personal growth

- supporting others.

Bray et al (2017) caution when goal setting it is important to remember that the peer support process for parents of children with disability is not a linear progression from 'surviving' (getting by whilst struggling to cope) to 'thriving' (experiencing grown and greater wellbeing). The journey is subject to good and bad days. The study found that the journey underpinning parents personal growth and journey travelled through adversity from 'being lost', 'being or finding a guide' and 'getting to a better place'.

Kramer et al (2017) emphasise that in a program where specific goals are created, these goals shouldn't be pursued at the expense of creating a meaningful relationship between the peers (although the creation of meaningful relationships could in fact be a goal).

In general, peer support has been defined by the fact that people who have like experiences can better relate and can consequently offer more authentic empathy and validation. It is also not uncommon for people with similar lived experiences to offer each other practical advice and suggestions for strategies that professionals may not offer or even know about. Maintaining its non-professional vantage point is crucial in helping people rebuild their sense of community when they've had a disconnecting kind of experience. (Reissman, 1989; Roberts & Rappaport, 1989).

Shilling V et al, 2013. Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. Developmental Medicine & Child Neurology. Volume 55, p. 602–609. Available at www.carersvic.com.au/wileypeersupport

Bray L et al, 2017. Parent-to-parent peer support for parents of children with a disability: A mixed method study. Patient Education and Counseling. Volume 100, Issue 8, p.1537-1543. Available at www.carersvic.com.au/sciencedirect

Kramer J et al, 2017. Feasibility of electronic peer mentoring for transition-age youth and young adults with intellectual and developmental disabilities: Project Teens making Environment and Activity Modifications. Journal of Applied Research in Intellectual Disabilities. Volume 31, Issue 1, p.e118-e129.

Riessmann F, 1989, Restructuring help: A human services paradigm for the 1990's, New York, NY Self-help Clearinghouse

Roberts L, and Rappaport, J 1989, Empowerment in the mutual help context: An empirical analysis of the value of helping others. Lansing MI: author

Caregiver support groups increase the knowledge that caregivers have, (Parker et al, 2010) increase their satisfaction with the caregiving experience, (O'Shea,2006) and reduce their loneliness and social isolation. (Munn-Giddings et al, 2007, Torp et al, 2008). Support groups can empower caregivers to overcome cultural and gender expectations and norms that have limited their caregiving capacity (Chan et al, 2008).

Parker G, Arksey H, Harden M. Meta-review of international evidence on interventions to support carers. York, UK: University of York Social Policy Research Unit, 2010.

O'Shea E. An economic and social evaluation of the Senior Help Line in Ireland. Ageing & Society, 2006; 26:267-284.

Munn-Giddings C, McVicar A. Self-help groups as mutual support: what do carers value? Health & Social Care in the Community 2007;15 (1):26-34.

Torp S, Hanson E, Hauge S, Ulstein I, Magnusson L. A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. Health & Social Care in the Community 2008;16(1):75-85.

Chan SM, O'Connor D. Finding a Voice: The Experiences of Chinese Family Members Participating in Family Support Groups. Social Work With Groups 2008;31(2):117-135.

There is evidence that peer supporters can benefit from an opportunity to 'give back', with their experiences having meaning for others (Schippke J et al, 2015; Sartore G et al, 2013; Heisler M et al, 2007). For example, Sartore G et al (2013) highlight evidence that peer supporters report enhanced quality of life and a validation of their previous experiences. Similarly, Heisler M et al (2007) highlight evidence that volunteers who provide social support experience less depression, heightened self-esteem and self-efficacy, improved quality of life and improved health behaviours and outcomes.

Schippke J et al, 2015. Peer support best practice toolkit. Holland Bloorview Kids Rehabilitation Hospital. Toronto, Ontario. Available at www.carersvic.com.au/hollandbloorview

Sartore G et al, 2013. Peer support interventions for parents and carers of children with complex needs. Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD010618. DOI: 10.1002/14651858. Available at www.carersvic.com.au/cochranelibrary

Heisler M et al, 2007. "I Am Not Alone": The Feasibility and Acceptability of Interactive Voice Response-Facilitated Telephone Peer Support Among Older Adults With Heart Failure. Congestive Heart Failure. Volume 13, Issue 3, May/June 2007, p. 149–157. Available at www.carersvic.com.au/ncbi

AMAZE undertook an extensive literature review about peer support groups: *Literature Review, Best Practice in Peer Support* published in 2018. The key findings which you could quote are listed below. Alternatively check the literature review yourself for more examples of evidence-based peer support research.

While limited, there is emerging evidence that peer support may be valuable for families and carers of people living with illness or disability (Lindsay M et al, 2017; Schippke J 2015).

A systematic review of the evidence (Shilling V et al, 2013) regarding benefits of peer support for parents of children with chronic disabling conditions identified four key themes:

1. finding a shared social identity (fostering a sense of belonging, support, and empowerment, enabling parents to feel better able to cope, and reducing senses of isolation, loneliness, and guilt),

2. learning from the experiences of others (including through the exchange of practical information and problem solving),

3. personal growth (including through developing new skills and a growth in motivation and feelings of empowerment), and

4. supporting others (benefit to peer supporters in providing mutual and reciprocal support).

A subsequent study of a parent-to-parent peer support program for parents of children with disabilities in the UK identified the most important benefit as being the ability to share feelings, worries and anxieties with another parent who had travelled a similar journey (Bray et al, 2017).

Lindsay M et al 2017. Family bedside orientations: An innovative peer support model to enhance a culture of family-centred care at the Stollery Children's Hospital, Paediatrics & Child Health. Volume 22, Issue 7, p.387–390. Available at www.carersvic.com.au/oxfordacademic

Schippke J et al, 2015 Rapid evidence review: Peer support for Ontario families of children with disabilities. Toronto, ON: Evidence to Care, Holland Bloorview Kids Rehabilitation Hospital. July 2015. Available at www.carersvic.com.au/hollandbloorview_pdf

Shilling V et al, 2013. Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. Developmental Medicine & Child Neurology. Volume 55, p. 602–609. Available at www.carersvic.com.au/wileypeersupport

Bray L et al, 2017. Parent-to-parent peer support for parents of children with a disability: A mixed method study. Patient Education and Counseling. Volume 100, Issue 8, p.1537-1543. Available at www.carersvic.com.au/sciencedirect

The definition of "peer support" developed by Dennis C (2003), following a literature review of peer interventions, is the definition most commonly referenced in the literature regarding peer support in the health sector (see for example, Trickey H, 2016; de Vries L et al, 2014; Dale et al, 2012). Dennis (2003) defined peer support within a healthcare context as:

the provision of emotional, appraisal and information assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population.

Dennis C, 2003. Peer support within a health care context: a concept analysis. International journal of nursing studies, Volume 40, Issue 3, Pages 321–332.

Trickey H, 2016. Peer support: how do we know what works? Perspective. Issue 31, June 2016. Available at www.carersvic.com.au/orcauk

de Vries L, 2014. Peer support to decrease diabetes-related distress in patients with type 2 diabetes mellitus: design of a randomised controlled trial. BMC Endocrine Disorders. Volume 14, p.21. Available at www.carersvic.com.au/bmc

Dale J et al, 2012. What is the effect of peer support on diabetes outcomes in adults? A systematic review. Diabet Med. Volume 29, Issue 11, Page 1361

REFERENCE: AMAZE, Literature Review: Best practice in peer support, Carlton South, April 2018. Available at www.carersvic.com.au/amaze

WHERE TO APPLY FOR GRANTS AND FUNDING

The most comprehensive guide we know of about where to and how to apply for grants and funding comes from www.ourcommunity.com.au

This includes grants and funding from government, businesses, philanthropic foundations and not-for-profit organisations.

There are also ideas about crowdfunding and setting up donation platforms.

Our Community fundraising and grants information can be found here:

- www.fundingcentre.com.au
- www.fundingcentre.com.au/help/grantseeking-basics

Probono Australia links to current grants openings via Strategic Grants and also have helpful grants application advice www.probonoaustralia.com.au/grants

Other sources for seeking funding and grants include:

- state government grants for self-help groups www.dhhs.vic.gov.au/grants-and-assistance
- a full list of Victorian state government grants www.vic.gov.au/grants
- most councils in Victoria offer annual community grants for small groups. Visit your council's website and search for "community grants" or simply call and ask
- local banks and businesses can also be a good source and worth developing a relationship with. For example, the Bendigo Bank www.carersvic.com.au/bendigobank
- or community organisations such as Lions Clubs.

For details on becoming incorporated and other legal requirements for receiving grants and funding see Registering and Incorporating a Group on page 1.

Grant Application Tips

- Plan your project properly.
- Read the guidelines and criteria.
- Answer the questions.
- Don't replicate what's already being done in your area.
- The funder wants to know what the benefits and outcomes will be.
- Spend time on your budget.
- Get someone else to proofread.

EXAMPLES OF SUCCESSFUL GRANT APPLICATIONS

Summary examples of successful grant applications through the NDIS 2018 Disabled People and Families Organisations (DPFO) grant round.

Organisation: Julia Farr Association Incorporated (Auspicee: Disability Elders of all Ages)
State South Australia
Project Title Peer Power for People Living with Physical Disability in South Australia
Primary Disability All people with disability
Project Description Organisational Capacity Building Support Disability Elders of All Ages to develop a strategic plan and a peer network for adults living with physical disability in South Australia. A Project Officer will recruit, train and develop the capacity of four Peer Connectors to facilitate peer support groups. Individual Capacity Building Support Disability Elders of All Ages to provide peer support groups and training to increase members' skills in self-directed support, self-advocacy, collaboration and leadership.

Organisation: Plumtree Children's Services Inc (Aupicee: Parents Empowering Parents)
State New South Wales
Project Title Parents Empowering Parents (PEP)
Primary Disability All people with disability
Project Description ### Organisational Capacity Building Support Parents Empowering Parents (PEP) to become an incorporated association and to develop a constitution and appropriate governance structure, corporate plans and resources, including a website and information management systems. Enable the employment of a part-time PEP Peer Worker and support an annual PEP conference for parents, families and their children. ### Individual Capacity Building Support Parents Empowering Parents (PEP) to develop and deliver a program of parent education events including workshops, training, webinars, and family leadership programs, and an annual conference. Enable PEP to establish a peer support network, and to provide training programs and support networks to the families from a CALD background and to fathers and male carers of children with developmental delay and/or disability.

Organisation: Parents of Children With Special Needs Inc
State Western Australia
Project Title Kalparrin Strategic Planning and Peer Support
Primary Disability All people with disability
Project Description ### Organisational Capacity Building Support Kalparrin to appoint consultants to engage with their members, staff, Board, partners and other external stakeholders to review strategic and operational plans, and identify current and future member's needs. New business models will be considered for Kalparrin in order to develop a corporate plan, identify purpose, strategic imperatives, critical success factors, strategic risks and key deliverables. ### Individual Capacity Building Employ a Peer Support Officer to consult with families and young people to map their information and support needs. The project will also recruit and train peer support volunteers to work with young people with disability, and will create and share information resources about engaging in social, economic and civic life.

Source: www.ndis.gov.au/community/grants/funded-projects.

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