# **AMAZE** Literature Review

# **Best practice in peer support**

## April 2018



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#### **Executive Summary**

Amaze has been funded to develop an evidence-based model of peer support suitable for autistic people, their families and carers. As part of this project, Amaze has undertaken a literature review of peer support models across the disability, healthcare and mental health sectors. This paper presents the findings of Amaze's literature review.

While 'peer support' has been interpreted differently across sectors, it generally involves a created social network for people, with similar characteristics and challenges, to share experiences and knowledge, and provide social support in a non-hierarchical and mutually beneficial way.

Globally, there is growing evidence that peer support may influence behaviour change and health and wellbeing outcomes for people living with a range of disabilities and conditions, including diabetes, asthma cancer, cardiovascular disease, mental illness, dementia and HIV and AIDS. However, a lack of adequate data and evaluation has limited the strength of the evidence to date. There is also emerging evidence that peer support programs may benefit some socio-economic and cultural groups more than others, including people in cultures and low and middle income communities in which stigma may otherwise prevent them talking about their experiences to friends or family, or otherwise having their social needs met.

Existing best practice toolkits for peer support currently include those developed by Peers for Progress in the United States (diabetes peer support) and the Holland Bloorview Kids Rehabilitation Hospital in Ontario (for families of children with medical complexity and other lifelong disabilities). Early evaluation shows that these toolkits have been effective to share best practice in peer support, with sufficient flexibility to be adapted to local contexts.

No one model of peer support can suit all purposes or participants as there are a range of social and cultural factors likely to influence how peer support will be best delivered and received. The most commonly utilised models of peer support are 1:1 or support group models, with variations in their levels of structure and flexibility, length and intensity and approaches to peer matching. They can exist across a range of settings (e.g. home, healthcare settings, community organisations, via telephone or internet technologies) and include a variety of roles (including mediators, educators, counsellors etc.) with varying degrees of involvement.

Each model of peer support has its own strengths and limitations. However, there is consistent emerging evidence that regardless of the model utilised, best practice in peer support will always involve the following key elements:

- co-design with participants, community members and other stakeholders, as well as a person and family centred approach to program implementation
- comprehensive assessment of community and organisational readiness
- strategic approach to program development, including; an assessment of the program's purpose, identification of a theory or theories of change, and functional components (i.e. topics to be covered)
- evidence-based determination of the best model or models for peer support (i.e. size [e.g. 1:1 or group], setting [e.g. home, healthcare setting, community organisation, online, telephone], level of formality, length and intensity, approach to peer matching, utilisation of a facilitator etc.)
- protocols, role descriptions and criteria for the recruitment of program participants
- protocols for training and supporting peer supporters
- quality data collection and robust evaluation.



#### 1. Introduction

Amaze has been funded to undertake a Victorian Department of Health and Human Services, Information, Linkages and Capability Building (ILC) project to develop an evidence-based model of peer-to-peer support ("peer support") suitable for autistic people, their families and carers – to reduce their social isolation and increase their sense of belonging and community connectedness.

As part of this project, Amaze has agreed to undertake a literature review of peer support models across the disability, healthcare and mental health sectors. This literature review highlights the range of peer support programs currently implemented across these sectors, with most evidence coming from the healthcare sector.

While the evidence is somewhat limited, there is consistent and emerging evidence that peer support can be a cost-effective way for people that have faced or are facing similar challenges to share experiences and knowledge, and provide social support in a non-hierarchical and mutually beneficial way (Heisler M, 2006). Peer support has been linked to a range of behaviour change and health and wellbeing outcomes across all sectors, although the approach to peer support and its outcomes vary across sectors. This is not surprising given the different philosophical underpinnings and objectives of each sector.

#### 2. Background

#### (a) What is peer support?

The main feature distinguishing peer support from other forms of support is that peers share key personal characteristics, circumstances or experiences (Simoni et al, 2011(a)). While peer support was specifically defined within some of the papers reviewed, there remains a lack of definitional clarity (Simoni et al, 2011(a)).

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 possess experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population.

According to Dennis C (2003):

- Emotional support involves expressions of caring, encouragement, listening, reflection and reassurance, in contrast to criticising or giving advice;
- Informational support involves the provision of knowledge relevant to problem solving and includes availability of relevant resources, independent assessments regarding a problem, alternative courses of action and guidance about effectiveness; and
- Appraisal support involves the communication of information that is pertinent to selfevaluation and the appropriateness of emotions, cognitions and behaviours. It may also include reassurance and motivational aspects to encourage persistence and resilience.



All three types of support (emotional, appraisal and information) are based on experiential knowledge, rather than arising from formalised sources (Dennis C, 2003). Support may be provided through multiple models (e.g. 1:1 face-to-face sessions, face-to-face support groups, online groups), across a range of settings (e.g. home, healthcare setting, community organisations, via telephone etc.) and incorporate a variety of roles (including mediators, educators, counsellors etc.) with varying degrees of involvement.

The definition of peer support by Sartore G et al (2013) is also commonly used in the health sector. Sartore G et al (2013) defined peer support as:

the existence of a community of common interest where people gather (in person or virtually by telephone or computer) to share experiences, ask questions, and provide emotional support and self-help.

The health sector peer support literature emphasises the importance of differentiating peer support from programs available via professional service providers. It emphasises that peer supporters should not see their role as a professional or service provider giving advice, but rather an equal, sharing their mutual experiences in a non-hierarchical and egalitarian way (Mead et al, 2006; Fisher E et al, 2014; Embuldeniya G et al, 2013; Walker G et al, 2013; Fisher E et al, 2010; Dennis C, 2003). Peer supporters must not seek to assess, advise or evaluate their peer, but rather share their experience (Mead et al, 2006). Dennis C (2003) cautions that "when peers are professionalized, their talents and accountability to the target population are shifted to the health-care system, diminishing their mutual identification, credibility and commonality with clients".

In the disability sector, there remains an absence of attempts to define of peer support. However, in their systematic review of peer support programs for autistic children (provided by children without disability) Chang et al (2016) define 'peer support interventions' as 'training typically developing peers (e.g. classmates) on behavioural and social strategies to engage children with ASD".

By comparison, in the mental health sector, peer support has been broadly defined by Lloyd-evans et al (2014) as:

support or services provided to people with mental health problems by other people who have experienced mental health problems.

It has also been defined by Mahlke et al (2104) as:

an evidence-based mental health model of care, which consists of qualified peer support providers who assist individuals with their recovery.

In contrast to the healthcare sector, peer support in the mental health sector often consists of a trained peer supporter who assist individuals with their recovery (Seeley J et al, 2016; Fuhr D et al, 2014; Mahlke et al 2014). In this sense, peer support in mental health refers to a mix of therapy and peer support whereby a peer delivers low-intensity interventions. The rationale behind this approach is that those receiving the interventions may respond better to a peer as they are more relatable and can share like experiences, and it may be more cost-effective (Fuhr D et al, 2014).

Accordingly, when establishing a peer support program, it will be important to consider the definition of peer support that will apply, particularly the balance to be reached between sharing experiences only, or providing a level of advice/therapy type services.



The launch of social media has led to an increase in solicited and unsolicited communication that occurs naturally and involves self-forming online communities (Naslund J et al, 2016). While self-forming online communities may be described as peer support in the literature (e.g. Naslund J et al, 2016) they have not been included in this literature review as they are not intentionally created, but rather are a naturally occurring social network (cf Simoni et al, 2011(a)). In contrast, studies regarding deliberately formed online peer support groups have been included in this literature review (i.e. Niela-Vilen H et al, 2014; Ali et al, 2015; Horgan A et al, 2013; MacLeod A, 2010).

#### (b) Who is a peer?

It is difficult to provide a single definition of "peer" as it will vary depending on the program, its target population and goals and objectives. Dennis C (2003) defines a peer as:

a created source of support, internal to a community, who shares salient target population similarities (e.g. age, ethnicity, health concern or stressor) and possess specific knowledge that is concrete, pragmatic, present-oriented and derived from personal experience rather than formal training.

In the health promotion context, Simoni J et al (2011(a)) outlines that a peer can range from natural helpers conducting autonomous activities that complement or support professional services (that have minimal engagement with the service provision organisation), to paraprofessionals that are fully integrated into a service provision organisation, i.e. peer professionals. Training requirements and compensation may increase along the continuum from natural helper to paraprofessional (Simoni J et al, 2011(a)). The appropriate place of a peer along this continuum depends on the goals and objectives of the program, the needs of its target population and the program's capacity to integrate peer workers (Simoni J et al, 2011(a)).

In contrast, and further to the discussion above, Dennis C (2003) states that peers (in the healthcare sector) do not generally work in professional programs or community organisations, extend existing services, or reach or motivate the population to use or comply with existing regimens of care. Dennis C (2003) and others are of the view that the professionalisation of peers can compromise their capacity to provide mutual support, based on their shared experiences (Mead et al, 2006; Fisher E et al, 2014; Embuldeniya G et al, 2013; Fisher E et al, 2010).

Regardless of where their role sits, peers must always function intentionally within a created social network or program and according to program protocols, rather than operating solely as part of a naturally occurring social network of family, friends etc. (Simoni et al, 2011(a); Dennis C, 2003). Peers are generally selected or volunteer specifically for their role within a purposely created social network or program (Simoni et al, 2011(a)).

Almost all of the studies reviewed for the purpose of this literature review were found to focus on peers that were engaged as volunteers and work outside of the organisation delivering the peer support program. For the purpose of this literature review, these peers are referred to as "peer supporters". Peer support in the disability context is broadly divided into two categories, peer support for people with disability and peer support for their parents/carers.



#### (c) Evidence of the outcomes of peer support programs across sectors

Globally, there is growing evidence that peer support may influence behaviour change and health and wellbeing outcomes for people living with a range of disabilities (Shilling V et al, 2013; Chat et al, 2009) and conditions, including diabetes (Dale et al, 2012), asthma (Kew K et al, 2017) cancer (Meyer A et al, 2015; Hoey et al, 2008), cardiovascular disease (Parry M, 2010), mental illness (Ali K et al, 2015; Fuhr D et al, 2014), dementia (Femiola C et al, 2017) and HIV and AIDS (Tolli M, 2012; Simoni et al, 2011(b)). However, a lack of data collection, clear objectives and goals, and rigorous evaluation has limited the strength of the evidence to date and largely precluded generalisation (Kew K et al, 2017; Meyer A et al, 2015; Ali K et al, 2015; Shilling V et al, 2013; Dale et al, 2012; Simoni et al, 2011(b); Fuhr D et al, 2014; Lloyd-Evans B et al, 2014; Boothroyd et al, 2010).

#### Diabetes

- Peer support programs have been used extensively over the past 20 years for adults with diabetes to achieve a range of outcomes, including improved glycaemic control, enhanced self-care, increased social support and improved mental health (Dale et al, 2012, Browne et al, 2016).
- Systematic reviews by the World Health Organization (2008) and by Dale et al (2012) found that peer support appeared to benefit some adults living with diabetes, but that the evidence was limited with respect to its effectiveness and suitability to the meet needs of particular individuals, populations and settings, how best to implement its specific components and the sustainability of its effects (Dale et al, 2012).
- The limitations in evidence have been found to result largely from a lack of well-designed program evaluations investigating all aspects associated with the design and implementation of different models of peer support, as well as cost effectiveness (Dale et al, 2012).
- However, a strategic initiative by Peers for Progress to promote best practice in peer support, including through the development of key functions for diabetes, is continuing to evolve and has been found to be effective to support program development, implementation and evaluation (Fisher E, 2012; Fisher E, 2010, Boothroyd et al, 2010). See discussion of Peers for Progress below.

#### Mental health

- Most of the literature on the topic of mental health revolves around systematic reviews of a broad range of programs that aim to measure the effectiveness of peer support in a recovery-oriented context<sup>1</sup>. They tend not to highlight best practices or specific strengths of programs and instead aim to evaluate whether peer support workers can provide a costeffective alternative to providing therapy-type services, compared to professionally trained clinicians.
- There is limited but emerging evidence that peer support in the mental health sector can positively influence patient's clinical and psychosocial outcomes, including increasing quality of life, hope, recovery and empowerment (Fuhr D et al, 2014; Lloyd-Evans, B et al, 2014; Mahlke C et al, 2014). There is evidence that other benefits may include: shared identity; self-confidence; helping others; developing and sharing skills; information and signposting; and challenging stigma and discrimination (Faulkner A et al, 2012).

<sup>&</sup>lt;sup>1</sup> 'Recovery' in mental health 'means gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self' (Department of Health 2018, Principles of recovery oriented mental health practice. Available at http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-n-servst10-toc~mental-pubs-nservst10-pri



• Mahlke C et al (2014) highlight that destigmatisation, at both the personal and system level should always be a key focus of mental health peer support.

#### Disability

- There is emerging evidence that people with disability can benefit from peer support programs when matched with peer supporters with disability (Kramer J et al, 2017) and peer supporters without disability (Siew C et al, 2017; Chang et al, 2016; Macleod A, 2010).
- 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; cf Schippke J 2015(a)). 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:

   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).
- A subsequent study by Kramer J et al (2017) assessed the feasibility of internet and telephone-based peer mentoring for transition age youth and young adults with intellectual and developmental disability. It found that electronic peer support can support people with intellectual and developmental disability to find solutions to perceived physical and social barriers, if a balance is fostered between addressing instrumental mentoring goals and developing a meaningful mentoring relationship, and if adequately supported by mentoring scripts and program supervisors.
- For autistic people of all ages, there is emerging evidence that peer support can provide a range of benefits, including: improved social, communication and play skills; increased ability to manage transitions; feelings of social connectedness and support; increased independence; networking opportunities and enhanced self-advocacy skills (Siew et al, 2017; Chang et al, 2016; Karoff et al, 2017; Macleod, 2010; Chan et al, 2009).

#### (d) Differential outcomes

There is emerging evidence that peer support may benefit some socio-economic and cultural groups more than others. For example, there is evidence that peer support for diabetes may be particularly important in countries where stigma otherwise prevents a person talking openly about their experiences or challenges to family, friends or others in the community, or otherwise meet their social needs (Shyamasunder A et al, 2016). 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. Similarly, peer support for women who have left or are in the process of leaving an abusive partner is found to benefit women who are unable to find the support they need through friends and families (either due to fear of stigma or judgment, or because support offered did not meet their needs) (Tutty L, 2006).



Systematic reviews of the evidence regarding the effectiveness of breastfeeding support interventions, including peer support interventions, have consistently found that it has a significantly greater effect on promoting breastfeeding and exclusive breastfeeding rates in low or middle-income countries, compared to high income countries (Jolly K et al, 2012; Sudfield C et al, 2012). A systematic review of peer support programs for smoking cessation in disadvantaged groups found that peer support for smoking cessation may be a greatest importance to disadvantaged groups who experience fewer opportunities to access such support informally (Ford P, 2013).

There is evidence that peer support may be especially beneficial when patients are facing challenging new developments in their disease, such as complications (Heisler, 2010, cited in de Vries L et al, 2014).

#### (e) Outcomes for children and young people

The evidence regarding the benefits of peer support for adolescents and young people across sectors remains limited. However, there is emerging evidence that peer support programs for autistic students (from preschool to university) can be effective if flexible in their approach, developed in close collaboration with students, peer supporters are well trained, program fidelity is measured, the program involves ongoing guidance from staff and is rigorously evaluated (Karoff M et al, 2017; Siew C et al, 2017; Chang et al, 2016).

Across the health sector the evidence is limited and there is a lack of methodological rigour in evaluations that have been conducted (Harden A et al, 2001). However, the European Guidelines for Youth AIDS Peer Education (2001) highlight particular considerations when engaging young people in peer support, noting that initially they may not have heard of peer support or have an understanding of what it involves. The guidelines also highlight unique challenges for young people engaging in peer support with known peers/ friends.

#### (f) Outcomes for peer supporters

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, the 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.

#### (g) Cost effectiveness

There is emerging evidence regarding the cost-effectiveness of peer support programs.

In the healthcare sector, there is evidence that peer support may reduce the length, and therefore cost of hospital stays (Johansson T et al, 2017). Furthermore, Peers for Progress recently conducted a literature review of economic evaluations of peer support between 2000 and 2014. It identified 15 cost-effectiveness studies and 12 other economic analyses of peer support interventions in the context of diabetes, mental health and substance abuse, breastfeeding and postnatal care, and primary care. These studies were found to highlight the economic value of peer support, using a variety of approaches. For example:

 Encourage: Diabetes Peer Advisor Program in rural Alabama – 59% probability of cost-saving, 55% to 93% probability of being cost-effective, depending on those included (e.g. higher likelihood of being cost-effective for those with greater need, those with depression or poorer baseline clinical status).



- Diabetes Initiative of Robert Wood Johnson Foundation: Cost per Quality Adjusted Life Year (QALY) = \$39,563 (well within \$50,000 criterion for good value).
- Preventing Re-hospitalization in Schizophrenia, Depression, Bipolar Disorder: Recovery Mentors provided individualised support, over 9 months: 0.89 vs. 1.53 hospitalizations, 10.08 vs. 19.08 days in hospital (p < 0.05).</li>
- Reducing Depression/Anxiety Disorders in India: Provided education about psychological problems, ways of coping, and interpersonal therapy delivered by lay health counsellors with primary care and psychiatric back-up. This resulted in 30% decrease in prevalence, 36% decrease in suicide attempts, 4.43 fewer days no work/ reduced work in previous 30 days (Peers for Progress, 2014).

In contrast, a systematic review of peer support programs for parents of children with chronic disabling conditions found limited evidence of the cost effectiveness of peer support programs for this group (Shilling V et al, 2013). In addition, Kramer J (2017), following review of a peer support program for young people with intellectual and developmental disabilities (IDD), by young people with IDD, found that peer support may not be feasible for community based organisations due to costs, particularly for ongoing support needed for peers and peer supporters.

Dennis C (2003) cautions that while potentially a cost-effective intervention in the healthcare sector, the possibility of exploitation or overburdening of peers may occur if they are inappropriately used as a replacement for professional services.

#### (h) Existing best practice guidelines/toolkits.

Best practice toolkits for peer support have been developed by Peers for Progress (diabetes peer support) and Holland Bloorview Kids Rehabilitation Hospital in Toronto, Ontario (for families of children with medical complexity and other lifelong disabilities).

#### (i) Peers for Progress

Peers for Progress is a global initiative of the American Academy of Family Physicians Foundation, developed out of the World Health Organization's Consultation on Peer Support Programmes in Diabetes, as a strategic approach to promote best practice in peer support for health globally (Boothyroyd R et al, 2010). It aims to strengthen evidence of the value of peer support through evaluation grants and providing a functional approach to peer support (Boothyroyd R et al, 2010).

Recognising that no one peer support program can suit all countries and cultures, Peers for Progress focussed on identifying key functional components of effective support that can be applied flexibility according to local needs. To support best practice in peer support for diabetes, it established four key functions, in partnership with stakeholders: assistance with daily management, social and emotional support, linkage to clinical care, and ongoing availability of support. These four standardised key functions have supported diabetes peer support programs to be introduced successfully across varied cultural settings and within diverse health systems, enabling local variation in the ways they are addressed. The functions have also established a template for program development and supported the development of consistent evaluation frameworks (Fisher E, 2012; Fisher E, 2010; Boothroyd et al, 2010). Fisher E (2012) highlights that standardized key functions can be applied in a wide range of settings.

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



<u>Development</u>: This part introduces key steps, considerations, and resources to help plan a program, assess community and organisational readiness, as well as recruit, select and train peer supporters.

<u>Implementation</u>: This part shares tips and tools to help manage retention and turnover of peer supporters, structure a constructive approach to supervision, and also reach and engage program participants.

<u>Evaluation</u>: This part outlines how to plan program evaluation, and provides example models and measures. In addition to common approaches, this part also introduces the concept of rapid cycle improvement, which allows a program manager to focus on short-term changes in order to continuously improve the program.

#### (ii) Peer Support Best Practice Toolkit, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

Holland Bloorview Kids Rehabilitation Hospital in Toronto, Ontario (HBKRH) have developed and disseminated an evidence-based Peer Support Best Practice Toolkit for families of children with medical complexity and other lifelong disabilities, freely available online at <a href="https://hollandbloorview.ca/teachinglearning/evidencetocare/knowledgeproducts/peersupportbest">https://hollandbloorview.ca/teachinglearning/evidencetocare/knowledgeproducts/peersupportbest</a> practicestoolkit.

The toolkit includes practical information highlighting key characteristics, challenges and relevant considerations when developing in person groups (peer led, professional led and combination of both), online peer support, parent matching. It also includes research evidence on best practices in peer support, case studies, template and links to helpful resources (Schippke et al, 2015(b)).

A review of the toolkit by Schippke J et al (2017) found that it was valuable to synthesize and share best practices in peer support. Strengths of the work include the integrated approach used to develop the toolkit (engaging stakeholders in its development) and the inclusion of both the published research literature and experiential evidence, including participant case studies (Eight months post launch, the peer support website received more than 2,400 webpage hits. Early indicators suggest high relevance of this resource among stakeholders (Schippke J et al, 2017).



#### 3. Best practice in peer support

No one model of peer support can suit all groups for all purposes; however, the weight of evidence demonstrates that the key, best practice components to any peer support program are those outlined in Box 3 and explored below.

#### Box 3: Overview of best practice in peer support

Co-design

D	evelopment			
Program development				
With participants and other stakeholders:				
- assess community and organisational readiness, including linkages with local health care and othe service providers as relevant				
<ul> <li>take a strategic approach to program develo purpose, identification of a theory or theories</li> </ul>	pment, including an assessment of the program's of change, and functional components.			
	r support based on evidence (i.e. size [eg. 1:1 or gronnline], level of formality, length and intensity of a facitator etc)			
- develop protocols, role descriptions and crit	eria for the recruitment of program participants			
- develop protocols for the training and suppo	rt support of peer supporters			
Im	olementation			
Prioritising a person and family centred appro designed with relevant stakeholders) for:	ach to implementation, development of protocols (			
- retaining and supporting peer supporters				
- reaching and engaging peer participants				
- mainintaining fidelity to structured program				
- sustaining behaviour change.				
Evaluat	ion			
In collaboration with participants, undertake a evaluation, including:	systematic, rigorous and robust			
- identifying the evaluation model at the outse	t			
<ul> <li>undertaking mixed-methods evaluation</li> </ul>				
<ul> <li>undertaking mixed-methods evaluation</li> <li>using realistic and holistic measures/ indicate</li> </ul>	prs			
	brs			

#### (a) The importance of co-design, and person and family centred programs

Across Australia, there is growing understanding of the importance of co-design in the development of programs and services for people with disability, ensuring that: the lived experience of people with disability and those who care for them is front and centre; and that people with disability, their families and other relevant stakeholders have input, ownership and confidence in the delivery of programs and services (Victorian Parliament, 2017; Victorian Government, 2017).



The importance of a person and family centred approach to programs for people with disabilities and their families is also becoming well recognised, ensuring that the they have a strong role in decision making and that any program is respectful and responsive to their individual needs, including cultural and linguistic needs (Victorian Parliament, 2017; Victorian Government, 2017).

There is consistent evidence across the health and disability sectors that peer support programs that are valid, culturally relevant, feasible and acceptable to participants are generally:

- co-designed with participants, community members and other stakeholders;
- implemented utilising a person and family centred approach; and
- evaluated, utilising a co-designed model of evaluation, and with ongoing participation and input from participants and other stakeholders (Karoff et al, 2017; Lindsay M et al, 2017; Trickey H, 2016; Peers for Progress, 2018; Skea et al, 2011; Cherrington A, 2012; Macleod, 2010; Svenson G, 1998).

A participatory realist synthesis of peer support programme evidence by Harris J et al (2015) found that where organisations, researchers and/or health professionals adopt an authoritarian approach to design for peer support programmes, rather than a co-design approach, they risk limiting the ability of peer supporters to exercise autonomy and use their experiential knowledge to deliver culturally tailored support. Conversely, if a negotiated approach to co-designing programmes is taken, peer supporters are enabled to establish meaningful relationships with people in socially vulnerable groups (Harris J et al, 2017).

Co-design of models is essential to identify how individual circumstances, including social and cultural backgrounds, may impact the model of support potential participants would find most feasible and acceptable (Karoff et al, 2017; Harris J et al, 2015; de Vries L, 2014; Fisher E et al, 2014).

Any materials to be used in peer support programs, regardless of the model, should also be cocreated using expert opinions and input from members of the target population to increase relevance and acceptability (Harris J et al, 2015). Any materials must be in the target population's language and reflect the way that language is used in terms of concepts and vocabulary (Harris J et al, 2015).

**Young people:** The review of a peer support program for autistic high school students (with nonautistic peer supporters) by Karoff M et al (2017) found that it was acceptable to the students as it was driven by the needs and preferences of participant peers and it belonged to the students, with guidance from staff. Kramer J et al (2017) similarly highlight that peer support programs for young people with disabilities will be most successful when driven by the needs and preferences of participating peers. In the program reviewed by Kramer J et al (2017) peers identified the barriers in their physical and social environments and then worked with peer supporters and staff to devise a plan to overcome these barriers and achieve goals. The European Guidelines for Youth AIDS Peer Education similarly highlight the importance of young people being approached by known intermediaries, fully informed about the peer support program, ensuring that their opinions are heard and that they are eventually given a sense of project ownership (with this relationship needing to be maintained throughout the program) (Svenson G, 1998).



#### (b) Program Development

An evidence-based and methodical approach to program development is essential, including; an assessment of community and organisational readiness; an assessment of the program's purpose, identification of a theory or theories of change, and functional components (i.e. range of topics to be covered); evidence-based consideration of the best model or models for the peer support program; protocols, role descriptions and criteria for the recruitment of peers and peer supporters; and protocols for the training and support of peer supporters.

A pilot intervention is encouraged to assess short-term outcomes, allow for early modifications to the program or training, if required, and inform longer-term evaluation (Cherrington A, 2012).

#### (i) Assessing community and organisational readiness

Professional staff from the organisation managing the peer support program must have the capacity to be responsible for program supervision, peer and peer supporter selection and training, monitoring of implementation, evaluation and handling of all overall logistics (Heisler M, 2006).

Accordingly, before an organisation develops a peer support program, it is important that they assess their capacity to do so. This may also involve an assessment of organisational culture and strengths, buy-in from stakeholders, funding availability, access to necessary facilities and resources and the availability of a dedicated staff member to co-ordinate the program (Peers for Progress, 2018).

A community assessment (whether of a defined geographical area and/or community of interest) is also essential to developing a program that is culturally relevant, valid, acceptable, effective and sustainable (Peers for Progress, 2018). A community assessment should aim to assess demand and understand the local culture. It should also aim to ensure that the program's target population is clear and that the program is tailored to local context (i.e. demographics and socio-economic factors), is designed to meet the true needs of that population (in support and delivery, i.e. model, time, location etc.) and is not 're-inventing the wheel' (Peers for Progress, 2018; Harris J et al, 2015; Power S et al, 2010; Dykes F et al, 2005). There is evidence that collaboration with both local and respected leaders, as well as ethnic specific institutions, professional organisations and academic and community organisations can be of particular value (Harris J et al, 2015).

A thorough community assessment also provides the opportunity to develop relationships with local organisations, with a view to establishing valuable community partnerships. These partnerships may then be utilised to build awareness and understanding of peer support programs among relevant service providers and community groups, encourage these organisations and groups to inform potential participants about the peer support program and improve participant's awareness of, and access to, local services (Peers for Progress, 2018; Browne et al, 2016; Harris J et al, 2015; Kounonen M et al, 2012; Heisler M, 2006; Dykes F et al, 2005).

A review of 26 government funded breast feeding initiatives in the UK (Dykes F et al, 2005) found that when health professionals were fully informed regarding the development of a peer support program, and were provided with some input into the program, it improved their understanding and acceptance of the program. It also increased their likelihood of referring patients to the program. The authors concluded that a diverse range of community partnerships are valuable to maintaining and sustaining peer support programs, by providing multiple access points (i.e. hospitals, clinics, drop in centres) through which clients may be referred to the program (Dykes F et al, 2005).



### (ii) Assessing the program's purpose, theory or theories of change, intended functions, outcomes and goals.

The literature regarding peer support in the healthcare sector emphasises the importance of asking "What is 'the gap' that peer support aims to fill? i.e. what is the function of the peer support program, and what does it aim to achieve that cannot be achieved through professional service provision (Mead S et al, 2016). For example, in relation to diabetes, the gap to be filled has been identified as the ongoing self-management of medication and psychosocial wellbeing, which most professionals do not focus on (Mead S et al, 2016). For cancer patients, there is evidence that social support needs (including for coping with death and dying, reducing isolation and managing survivor guilt) are often not met by health services, but that peers can be well positioned to provide this support (Meyer A et al, 2015; Power S, 2010). Breastfeeding peer support has been found to provide effective continuity of care after midwives cease their involvement in breastfeeding support (Burns et al, 2017). There is evidence that peers also support breastfeeding women differently to midwives, providing support as a "knowledgeable friend", normalising breastfeeding challenges and enhancing women's confidence with breastfeeding (Burns et al, 2017). For women who have left or are in the process of leaving an abusive partner, peer support has been found to provide women with social connections and support when they may otherwise have been isolated after leaving a shelter (Tutty L, 2006).

Once the purpose is clarified, SMART (i.e. Specific, Measurable, Attainable, Relevant and Timely) medium and long-term outcomes and goals should be set as early as possible with local stakeholders (community health workers, community groups), targeted community members and program participants.

Establishing a strong theoretical understanding of how a peer support model is intended to cause change, i.e. theory or theories of change, is considered a prerequisite to optimising its design and implementation (Trickey H, 2016; Harris J et al, 2015; de Vries L, 2014; Dale et al, 2012; Fisher E, 2012). Dale et al (2012) found that in relation to diabetes peer support, the underlying theories that inform the design of specific peer interventions, including the recruitment, training and supervision strategies, need more attention. There may be considerable scope for increasing the effectiveness of peer support through strengthening its theoretical foundations and linking this to the process involved in all aspects of implementation (Dale et al, 2012).

For peer support, each model is underpinned by social support theory, which aims to connect people with community resources and social networks to achieve behaviour change (Cherrington A, 2012).

A range of other theories of change can apply to peer support programs, but the most common are:

- Health belief model: aims to target individuals' perceptions (i.e. perceived seriousness, susceptibility, benefits, and barriers) of health or health-related behaviors to achieve behavior change.
- **Social cognitive theory:** aims to improve individuals' self-efficacy (i.e. an individuals' personal belief in their own ability to execute desired changes) to improve their self-management of health-related or other behaviours.
- **Empowerment model:** aims to increase an individuals' knowledge, confidence and personal skills to activate personal or systemic/community change (Cherrington A, 2012; Simoni et al, 2011).



Across the literature regarding diabetes peer support, and peer support for people with disability, there is a focus on initially identifying the intended 'functions' or 'themes' of peer support. For example, as discussed above, recognising that no one peer support program can suit all countries and cultures, Peers for Progress has focussed on identifying key functional components of effective support that can be applied flexibly according to local needs (assistance with daily management, social and emotional support, linkage to clinical care and ongoing availability of support).

**Parent support:** 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. Bray et al (2017) therefore analysed the effectiveness of the Scope (UK) parent-to-parent support program via the concepts underpinning parents' personal growth and journey 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).

#### (iii) Identifying the best model or models for peer support

There are a range of peer support models, varying in terms of purpose and size (i.e. 1:1 or group), setting (i.e. home, healthcare setting, community organisation, online or telephone), level of formality, length and intensity, and approach to peer matching. They also incorporate a variety of roles (including mediators, educators, counsellors etc.) with varying degrees of involvement (Faulkner A et al, 2012).

For example, face-to-face support groups can differ in their structure (e.g. meeting frequency; duration of program; length of each session; drop-in versus registration; use of curriculum versus open-ended), format, and the engagement of facilitators (Schippke J et al, 2015(b). Online peer support may be provided via discussion board, chat, e-mail, live meetings, one-to-one discussion, and/or open group forums. Communication may involve real-time discussion (synchronous) or reading and responding to messages when it is convenient for the user (asynchronous) (Schippke J et al, 2015(b); Niela-Vilen H et al, 2014).

To the extent possible, the model or models for peer support to be utilised for any given program should be determined based upon the evidence for these models and in collaboration with participants and other stakeholders (Meyer et al (2016); Kramer J et al (2017)). Appendix 1 provides an overview of the most common models of peer support – 1:1 face-to-face sessions, group sessions and online and telephone conversations – and identifies their strengths, limitations and best practice approaches.



#### • No one model of peer support fits all purposes and target groups

The evidence is largely consistent across all sectors that there is no one model for peer support capable of fitting all purposes and target groups. In particular, MacLeod A (2010) highlights that due to the heterogeneity of autistic people, no one specific model of support could possibly be suitable for all.

There are a range of social and cultural factors (including socio-economic status, location etc.) likely to influence how peer support will be best delivered and received (Dale et al, 2012; Qi L, 2015(b); Fisher E et al, 2014; Faulkner A et al, 2012; Fisher E et al, 2010; Boothroyd et al, 2010; Dale 2009; WHO, 2008; Heisler M (2006)). A lack of well-designed evaluations and inherent bias can also make it difficult to identify elements of peer support models that may have achieved important outcomes for similar peer support groups (Dale et al, 2012).

Regardless of the particular model utilised, people with disability require constant, stable support, that is flexible and customised to the individualised needs of the participants and is provided in a comfortable peer-to-peer environment (ideally of the peer's choosing for 1:1 support) (Siew et al, 2017; Karoff et al, 2017). Time is also a key consideration as parents with limited resources are likely to prioritise the care of their child over time for themselves (Shilling V et al, 2013).

Across sectors some studies have identified evidence (although at times, inconsistent) that one model may be preferable over another in some contexts. These studies should be acknowledged as they highlight many of the strengths and limitations of the different peer support models. For example:

- Diabetes: A meta-analysis of randomized controlled trials by Qi L et al (2015) found that 1:1 support (by trained peer supporters, trained over 8 to 32 hours with training focusing on communication skills, including empathic listening, helping participants clarify their values and life goals, problem-solving and assertiveness) may be more effective for diabetes peer support than group support as 1:1 support is informal and more flexible (although it should be noted that the only outcome measured was improved glycaemic control in patients with type 2 diabetes). A survey of diabetes peer support participants in Australia undertaken in 2015 by the Australian Behavioural Centre for Research in Diabetes (ABCRD), found that the most commonly preferred mode of diabetes peer support was online (38%), followed by group support (26%) (Browne et al, 2016).
- **Disability**: Isolated studies of peer support in the education/ transition support context have found that while the model of support should always be determined on a case-by-case basis, in collaboration with peers, there is a growing focus on online peer support as (properly supported) this can be more accessible to people with social difficulties (Karoff et al, 2017; McLeod A, 2010).
- **Parents of children with dyslexia**: Qualitative evidence from a peer support program for parents of children with dyslexia that parents with high levels of stress may not be satisfied with the level of emotional support provided through a group, with individualised support being better suited to their needs (Bull, 2003).



• Breast feeding: The review of an integrated model of breast feeding peer support (incorporating 1:1 peer support and group classes) found that while 1:1 support decreased the hazard of discontinuing breast feeding (regardless of whether support was provided at home or in the clinic) the group education classes did not appear to be beneficial for improving breastfeeding outcomes in this population (Rozga M, 2016). To the contrary, a qualitative study conducted by Hoddinott P et al (2006) of participant perception of groupbased and 1:1 breast feeding peer support found that breastfeeding mothers will engage in peer support if there is net interactional (verbal, visual, emotional and gustatory) gain and minimal risk of a negative experience. 1:1 peer support was perceived as a greater to risk to confidence and empowerment than group-based support (Hoddinott P et al, 2006). 1:1 support was perceived as being more intense, with more perceived pressure to follow individual advice and less flexibility in attendance.

A systematic review of the evidence of peer support for breastfeeding duration and exclusivity compared to usual maternity care, by Renfrew MJ et al (2012), found that face-to-face support was associated with a larger effect than telephone support. The authors also found that support that is only offered reactively (i.e. when the women are expected to initiate the contact) is unlikely to be effective, women should be offered ongoing visits on a scheduled basis, so they can predict that support will be available. The authors concluded that support should be tailored to the needs of the setting and population group (Renfrew MJ et al, 2012);

- **Cancer**: A systematic review of cancer peer support programs found that 1:1 face-to-face and group internet peer support programs have most effect and should be given priority, but that other models shouldn't be dismissed until further research is conducted (Hoey L et al, 2008).
- **Mental health**: A systematic review of the effectiveness of peer support for people with severe mental illness and depression on clinical psychosocial outcomes found some evidence that interventions were more effective when delivered 1:1 than in a group (Fuhr D et al, 2014)

In many cases, where feasible, a combination of approaches may be appropriate (Heisler M, 2016; Dale et al, 2012). There is evidence that best practice may be for organisations to make a range of peer support models available for participants to choose from. For example, Meyer et al (2016), following their review of cancer peer support programs, recommended that future research explore the benefits for participants of choosing among 1:1 or group delivery models. This approach would recognise that peers have different expectations regarding support, different physical and social circumstances, including time and distance, and different reasons for preferring to communicate 1:1 or via a group. Similarly, Kramer J et al (2017) recommended that transition age youth and young adults with intellectual and developmental disabilities involved in peer support programs be given a choice on their preferred mode of communication.



#### • Structure versus flexibility

Regardless of the peer support model utilised, a careful balance must be found between providing a clear structure for the program and enabling adequate flexibility for it to be adapted to individual needs. For example:

- Siew et al (2017) highlighted the importance of flexibility in peer support for **autistic people** given the individual needs of autistic people vary greatly. The authors found that flexibility in programming allows for it to be tailored to individual needs, i.e. covering a broad range of topics and then honing in on what participants were most receptive to.
- Kramer J et al (2017) highlight the importance of ensuring peer support programs for **young people** with intellectual and developmental disabilities are flexible and customisable to the needs of the group and individuals within it.
- The review of a peer support program for **autistic high school students** by Karoff M et al (2017) noted the importance of the program being flexible and customised to the needs of the individuals involved, as well as providing frequent opportunities for uncontrived, authentic interaction with non-autistic peers.
- Tutty L's (2006) evaluation of a peer support service for **women who have experienced abuse** highlighted the importance of finding an appropriate balance between providing structure and information/ curriculum, while still allowing time for the women to tell their stories in a safe and respectful setting.
- The **Hearing Voices** network comprises loosely structured groups that aim to create a judgement free zone where there is no implication that hearing voices is pathological. A review of this program found that the focus on maintaining a natural flow dependant on participant needs, rather than moving from one predetermined topic to another, contributed to a more egalitarian approach, a reduction of power dynamics and feelings of self-validation (Dillon J et al, 2013).

By comparison, following the 2015 survey of diabetes peer support participants in Australia (Browne et al (2016) concluded:

Previous research indicates that peer support combined with structured or semi-structured diabetes education is particularly effective. While informal, unstructured gatherings of people with diabetes have their place and likely serve many positive purposes for those who participate, they can be hard to sustain and difficult for new members to find and access. We recommend moving towards a system that includes options for structured peer support programs that have infrastructure such as peer leader training, curricula, and topic-based discussions to ensure maximum effectiveness and longevity of the program; optional social elements can be incorporated into a structured program.

• The necessary length and intensity of peer support

While the evidence is limited, in a health context, it supports the funding of peer support programs to operate for at least three years (Harris J et al, 2015), and involve moderate to high frequency of contact (at least one contact per month) (Qi L et al, 2015). As above, consultation with potential participants, participants in previous peer support groups and other community stakeholders would no doubt be essential to determining the most feasible and acceptable frequency/ duration of the program for participants (de Vries L, 2014).



There was significant variation in the length and intensity of peer support programs reviewed. Some ran for a set amount of time (i.e. six weeks), others were ongoing. Some involved frequent contact (weekly) and others once every six months.

A realist review of peer support evidence by Harris J et al (2015) highlighted evidence that supports the funding of longer-term peer support programs (at least three years) to establish relationships with community partners, as well as establishing relationships between participants. Harris et al (2015) note that researchers evaluating community initiatives have pointed out that it is unrealistic to achieve outcomes related to behaviour change in a time period that is less than two years and that any peer support program should be funded for at least three years to enable collection of data on both short- and long-term goals.

- **Diabetes**: In diabetes peer support groups, there is some evidence that increased frequency of contact may be associated with greater effects (improved self-management of insulin) (Qi L et al, 2015; Piette J et al, 2013). For example, a meta-analysis of randomised controlled trials regarding to the effectiveness peers support for adults with type 2 diabetes to improve glycaemic control found that priority should be given to programs with moderate or high frequency of contact (one or more contacts per month), compared to low frequency of contact (less than one contact per month) (Qi L et al, 2015). It is unclear whether this is due to the nature of the goal, which may require frequent reinforcement. No significant variance in outcomes was found to be linked to the length of interventions (Qi L e al, 2015).
- **Breastfeeding**: A systematic review of peer support for breastfeeding in the UK (Jolly K et al, 2012) found that peer support had a greater effect on breastfeeding rates when given at high intensity and only delivered in the postnatal period, although no differences were observed of its effects on *exclusive* breastfeeding rates by intensity or timing. Peer support provided at a low intensity (<5 planned contacts) was found to be ineffective for any breastfeeding (Jolly K et al, 2012). A systematic review of peer interventions conducted globally by Kaunonen M et al (2012) found that only continuous breastfeeding support produces effective results. As above, this may be related to the nature of the goal, which requires frequent reinforcement.
- Peer matching

A key element of peer support is the creation of a shared identity, between people with 'similar characteristics' (Dennis C, 2003), which creates an environment that is more conducive to sharing (Faulkner & Basset 2012; Dennis C, 2003). However, what is meant by 'similar characteristics' may be open to interpretation (Trickey H, 2016). As queried by Trickey H (2016), following a review of the literature on peer support for breastfeeding mothers:

Do we mean social group, local area, age, education, or sense of humour? What sort of length or extent of 'experiential knowledge' is necessary? Does a mother supporting another with a perinatal mental health issue need to have experienced the same mental health problem? And does it matter how long ago? How much and what type of training will be necessary to integrate and augment experience? Interventions vary in the emphasis they place on 'matching' peers and the extent to which 'peerness' is considered an active ingredient in the intervention.



Peers for Progress (2018) advise that in addition to sharing experience with a disease or condition, peer supporters should be similar to the population profile of the participant, i.e. in age, ethnicity, language or other personal characteristics. People with character traits pertinent to developing quality relationships should also be sought, i.e. empathy, social and communications skills. Time availability should also assessed (Peers for Progress, 2018; Lindsay M et al, 2017).

Some studies have found that peers are best matched by diagnosis and, in particular, severity and daily impact of diagnosis. For example, Heisler M et al's (2007) review of a peer support program for older adults with health failure found that the most successful matches were between people that had similar disease severity and challenges (as participants felt they could learn from and contribute to their partner's heart failure management). Similarly, among cancer patients Skea Z et al's (2011) qualitative study found a preference for matching by severity in order to avoid anxiety or guilt, if paired with those with a worse prognosis, or envy, if paired with those with better health status.

However, other studies have found that the experiences of matched peers need not be identical and that other shared characteristics may be equally or more pertinent (Sartore G et al, 2013). A systematic review by Shillings V et al (2013) of the evidence regarding peer support for parents of children with chronic disabling conditions found that the need for a close match in parents' experiences was variably reported.

An evaluation of one-to-one support suggested that the most successful matches occurred when parents perceived similarity not only in their children's situations, but also in parents' personalities and social backgrounds. When parents perceived differences in the challenges faced by their children or in their own personalities and values, peer support was less successful. Not all studies, however, reported that close matching by diagnosis was necessary. Many issues are common to all families of disabled children, and for some parents in group settings this was enough to form the identity.

Fisher E et al (2014) similarly highlighted that peer matching should not always be simply on the basis of diagnosis, as this may reflect an inappropriate assumption that a person's diagnosis controls their views of themselves and their preferences in peer support. Fisher E et al (2014) recommends that depending on the population and the nature of the problems faced, it may be more important that supporters are seen as possessing similar demographic characteristics, coming from the same community, facing similar obstacles (Fisher E et al, 2014). Mead S et al (2016) and Simoni J et al (2011(a)) highlight that while some groups will have a shared experience of diagnosis, others may have a shared negative experience of treatment and support (Mead S et al, 2016; Simoni J et al, 2011(a)). Sartore G et al (2003) reported that parents who are in the early stages of adjusting to a diagnosis may benefit from the expertise of parents with children diagnosed some time ago (Sartore G et al, 2013). There is also evidence that peers closer in age have an increased likelihood of providing effective peer support (de Vries et al, 2014).

Shilling V et al (2013) note that whether the support being offered is 1:1 or group based may impact on the importance of matching by diagnosis, and that this is an area where further investigation and evidence is required.



If a peer support program is to be provided via a 1:1 model, best practice may be enabling each peer to select their own peer supporter where feasible and practical. For example, a qualitative review of a breastfeeding peer support program by Hoddinott P et al (2006) found that women should be empowered to select a 1:1 peer for themselves, via initial group sessions. The authors found that group support provided women with a safe setting and time to select a 1:1 peer for themselves, based on trust, personality and communication skills (Hoddinott P et al, 2006). They found that when women were empowered to select peers themselves they reported feeling empowered, confident and having a positive social experience. In comparison, having a professional select the 1:1 peer supporter was perceived as a more risky and intense strategy (Hoddinott P et al, 2006).

In the disability sector, it should be noted that many of the programs involve the pairing of people with disability and people without disability (Chang et al, 2016). For example, this has often involved training typically developing peers on behavioural and social strategies to engage autistic children (Chang et al, 2016). This may have the dual effect of destigmatisation and raising awareness and understanding of disability (Siew C et al, 2017; Karoff et al, 2017).

For example, Chang Y et al, 2016, highlights five successful peer support programs for autistic students across all ages (from preschool to high school), delivered by peer supporters without disability. Siew C et al (2017) reviews a peer support program for autistic university students paired with non- autistic allied health students (Siew et al, 2017) who gave practical support, finding that this approach created a supportive social network with positive impacts on communication, transitions, management of academic work and emotional regulation. Other programs, which functioned in schools, paired children with disabilities with 'buddies' to help bridge the communication gap (Karoff M et al, 2017; Chan et al 2009).

If peers are to be matched by a professional, a criterion for matching peers should be established and driven by any identified wishes, priorities or concerns of participants (Schippke J et al 2015(b)).

#### • Settings (including online peer support)

As discussed above, there is strong evidence that where feasible and practical, participants should determine whether they participate in a peer support model face to face, or via telephone or online mechanisms.

With respect to face-to-face support (whether 1:1 or group-based), there is little evidence to suggest that programs are more effective if provided at home, in a community centre or another location (Rozga M 2016). Of greatest importance is that the venue is accessible to all, including that it is local, accessible by public transport, is culturally appropriate and, where appropriate/ necessary, can accommodate children (Schippke J eta I, 2015(b); Tang et al, 2014). Participants should always be engaged in the decision about where they meet to ensure they feel safe and comfortable sharing their experiences (Karoff et al, 2017; Harris J et al, 2015; de Vries L, 2014; Fisher E et al, 2010).

There is emerging evidence regarding the effectiveness and preference for support provided via online mechanisms.



#### Online peer support

A systematic review conducted in 2014 of internet-based peer support interventions, and their outcomes for parents, found that internet-based peer support provided mostly informational support (based on professional sources and other parents' experiences) for parents and was accessible despite geographical distance or time constraints (Niela-Vilen H et al, 2014). It found that while internet-based peer support has some effect on parenting skills and mental wellbeing, the evidence was limited due to the lack of experimental design (Niela-Vilen H et al, 2014). The review also highlighted the different ways mothers and fathers utilised online peer support. For mothers, internet-based peer support provided emotional support, information and membership in a social community. For fathers, it provided support for the transition to fatherhood, information and humorous communication. Mothers were more active users of internet-based peer-support groups. The authors concluded that fathers should be asked what kind of support groups they would be motivated to be involved in and what kind of affirmation they need in fatherhood (Niela-Vilen H et al, 2014).

A systematic review of the evidence regarding the effectiveness of online peer-to-peer support for young people with mental health problems found an overall lack of high-quality studies examining online peer-to-peer support for young people. Nevertheless, there is also a growing amount of support for the impact of online peer support in mental health, including that it can improve coping strategies, emotional well-being, supportive communication, lower levels of emotional distress and positive effects for depressive symptoms (Ali et al, 2015). The review concluded that given the majority of young people are using the internet routinely, further research should be undertaken to explore the role that peer-to-peer support might play in assisting young people with mental health problems (Ali K et al, 2015).

The evaluation of an online peer support forum for university students with depressive symptoms found that it had a positive impact as: the anonymity of the site allowed students to share their feelings for the first time; it helped students identify others with similar experiences; and it allowed for students to experience the benefits of peer support in their own time and without geographic constraint, while at the same time avoiding the challenges associated with interpersonal interactions (individuals may choose to passively consume information without interacting) (Horgan A et al, 2013). However, Horgan A et al (2013) also emphasised that for an online forum to be successful, someone needs to be working on the website fulltime – especially in its early stages (i.e. posting new threads or articles from the internet to entice discussion).

An earlier study by MacLeod, A (2010) into online peer support for adolescents 'with Aspergers Syndrome' similarly found an online peer support program, developed in collaboration with autistic students, provided a safe space to share personal experiences. Participants reported that online interaction enabled them to be more reflective and less inhibited than they may have been in verbal discussions. Some participants also reported that they enjoyed the benefits of passive use of the online peer support program as, although they may not post, they felt less isolated (MacLeod A, 2010).



#### • Facilitation of peer support groups (face to face and online) by a professional

There is evidence that professional facilitation of support groups (particularly online) may enhance their effectiveness; however, the evidence regarding the ideal role of group facilitators is varied and limited.

For example:

- **Breastfeeding**: Hoddinott P et al's (2006) qualitative study of women's perceptions of breastfeeding peer support programs found that there was strongly expressed preference for a health professional, preferably one who also had personal breastfeeding experience, to be present at groups to help counteract extreme views and help women to distinguish between fact, anecdote and myth. By comparison, the review of government-funded breastfeeding peer support programs in the UK by Dykes F et al (2005) found that the most successful 'drop in' centres associated with peer support schemes were those that operated informally, with peer supporters taking a central role and health professionals having a background facilitative role.
- Diabetes: In diabetes peer support, it has been found that having discussions moderated
  predominantly by participants rather than a facilitator can increase participation, enhance selfreflection and help participants feel empowered (Shyamasunder A et al, 2016). The 2015 survey
  of diabetes peer support participants in Australia by the ABCRD found a preference for peer
  support groups to be facilitated or moderated by either health professionals or trained, 'expert'
  peers to ensure that discussions are evidence based and relevant and that participation is
  encouraged equally from all members (Browne et al, 2016).
- Mental health: It has been found that while groups can function well without professional guidance, it is preferable to have at least have professional guidance in the initial stages as groups otherwise tend to peter out (Castelein et al 2008). For example, the FRIENDS program aims to develop long-term relationships for people with a psychiatric disability through weekly group support meetings as well as recreational outings as a group. Groups start with professional guidance, which is gradually reduced. Individuals are also identified as role models and are given opportunities to lead.

A systematic review of the evidence regarding online peer support for young people with mental health problems found that the majority of discussion groups were facilitated by health professionals, researchers or consumers. However, there was limited information on facilitators, their level of skills, their engagement with the discussion group or the type of facilitation used. It recommended that future studies include these details to shed light on which level of facilitation works best for participants (Ali K et al, 2015).

There is evidence that a professional facilitator can be particularly valuable to facilitate online peer support groups, including by initiating discussions, monitoring safety, answering questions, and confirming information validity (Schippke J et al, 2015(b); Browne et al, 2016; Niela-Vilen H et al, 2014; Kaplan K et al, 2011). Kaplan K et al's (2011) review of internet peer support for individuals with psychiatric disabilities found that without a moderator, online peer support is often unhelpful and causes psychological distress for participants.

Across a range of models (i.e. face to face, online and via telephone) facilitators can also be valuable to facilitate a healthy rapport between peers and identify any negative impacts that may be emerging, for example, where partners are experiencing the same relationship differently or a person is feeling that another participant does not value their contribution (Embuldeniya G et al, 2013).



If a professional moderator or facilitator is involved in a peer group, it is important that they understand their role is to manage group interpersonal processes rather than to provide counselling or psycho-education (Sartore G et al, 2013; Mead et al, 2016).

Facilitator training is essential to ensure that principles, approaches and theories of the overall peer support program are put into practice. It also equips facilitators to safeguard the wellbeing of the group and encourage equal participation by all members (Browne et al, 2016; Dillon J et al, 2013). In mental health peer support, Dillon J et al (2013) find that facilitators should possess the following skills: lead by listening, enable processes as decided by the group, emphasise belief that each group member has deep wisdom and expertise about ways of managing problems, non-judgemental attitude and self-awareness.

#### (iv) Recruitment of peers and peer supporters

The European Guidelines for Youth AIDS Peer Education, 1998, highlight peer supporter recruitment and training to be the most challenging, yet important factor in the success of a peer support program (Svenson G, 1998; Tolli M, 2012). A review of government-funded breastfeeding programs in the UK found that the most effective projects developed clear guidelines for recruitment, selection, training and support of peer supporters, combined with in-built flexibility (Dykes F et al, 2005).

Peers for Progress (2018) emphasise that the appropriate process for recruiting peer supporters may vary between programs and should be tailored to fit each given program's objectives and context. However, the following should be developed:

- a clear criteria and procedure for recruiting peers and peer supporters to ensure that the relationship meets the needs of both the participant and the peer supporter
- a role description to ensure peer supporters understand their role and its parameters (see also Parent to Parent USA; Schippke J et al 2015(b); Mahlke, C et al, 2014; Walker G et al, 2013; WHO, 2008; Heisler M, 2006)
- protocols for their training, supervision and support.

The recruitment process for all participants should be developed in collaboration with community groups to ensure all relevant social and cultural factors are taken into account, as well as any other issues that may impact uptake and attendance, such as access to local services, transport and safety (Harris J et al, 2015).

The review of breastfeeding programs in the UK by Dykes et al (2005) found that a comprehensive publicity strategy was crucial to community receptivity and for effective uptake of peer support programs. The use of a brand name for the peer support program was found to be the key to success in marketing, for example 'Bosom Buddies'.

#### • Criteria for recruiting peers and peer supporters

'Peer' and 'peer supporter' should be defined for the purpose of the peer support program (WHO, 2008). The definition may then be translated into the criteria for recruiting participants.



For example, the criteria may include necessary personal attributes (i.e. age, ethnicity, language) or experiences (i.e. diagnosis or other shared experiences explored above with respect to peer matching). For peer supporters, it may also include the characteristics individuals should bring to these roles (i.e. communication and listening skills, proper motivations (Svenson G, 1998; WHO, 2008). Detailed information should also be sought from prospective peers to maximise the appropriateness of any peer match, and the effectiveness of the program, such as reasons for seeking support, the qualities they hope for in a mentor, and any unique preferences or issues related to the match (Parent to Parent USA; Schippke J et al 2015(b)).

Of note, the systematic review of the evidence regarding diabetes peer support undertaken by Dale et al (2012) found that further evidence is needed regarding the characteristics of individuals who are most suited to becoming peers and peer supporters. The authors also noted that existing evidence may be biased as those who choose to participate in studies may be more favourably disposed towards, and so gain more benefit from, the program than those with lower expectations about its relevance to their needs (Dale et al, 2012).

#### • Role description and protocol for peer supporters

A clear role description for peer supporters (accompanied by training, discussed below) is essential to ensuring peer supporters understand their role and its parameters, i.e. being clear a peer supporter's role is not to provide professional advice, but rather to share their mutual experiences in a non-hierarchical and egalitarian way (Mead et al, 2006; Fisher E et al, 2014; Embuldeniya G et al, 2013; Walker G et al, 2013; Fisher E et al, 2010; Dennis C, 2003). A review of evidence regarding peer support in mental health by Mahlke C et al (2014) found that studies highlighted the need for clarification of core competencies, helping skills and boundaries.

Peers for Progress (2018) also encourage the development of a protocol for peer supporters so they know how to carry out their tasks and work with others and to help establish quality assurance and quality improvement measures. According to Peers for Progress (2018) a well-developed protocol should:

- describe key tasks and associated tools (e.g. action plan)
- detail various situations that a peer supporter may encounter when reaching or interacting with a participant, and how to react
- outline scenarios during which a peer supporter should ask for help, and guidelines for how to address those issues with the supervisor or relevant team members.

The protocol may also contain information about "frequency and timing of peer supporter contact, sample scripts for telephone support, and approaches to common challenges and potential solutions. Intervention protocols put the skills and knowledge of peer supporters into context by capturing their work in action." (Peers for Progress, 2018).

#### • Protection of participants, including privacy management

Best practice should ensure peers are protected to the greatest extent possible. This may include through peer supporters receiving criminal record and vulnerable sector clearances, reference checks and baseline health screenings (Lindsay M et al, 2017).



Privacy issues should also be considered, including whether peer supporters should know basic information about peers prior to a program commencing so they may be better matched. For example, in the peer support program for families of children in hospital, reviewed by Lindsay M et al (2017) it was determined that peer supporters should have access to the following information prior to visits commencing: family names and experience being in hospital; patient name, age and length of stay; whether the patient's situation involves trauma, an unexpected diagnosis or delayed length of stay; whether the family is from out of town and has access to personal supports; and general description of any safety issues or circumstances that will likely impact the visit. If basic information (such as that identified in Lindsay M et al, 2017) is to be shared, the developing of information sharing guidelines should be considered in alignment with privacy laws (Lindsay M et al, 2017). A confidentiality agreement should also be signed by both peers and peer supporters before interactions begin (Lindsay M et al, 2017).

#### (v) Training for peer supporters

Ongoing training and support for peer supporters increases retention, participant satisfaction and the likelihood of a successful peer support program (Harris J et al, 2015). Peer supporters also benefit personally from training as it can have an empowering effect on them (Kounonen M et al, 2012).

The development of standardised curriculum and training, or a training protocol, can help ensure the sustainability of peer support programmes (WHO, 2008). For the purpose of breastfeeding peer support, a standardised training program has been developed by the WHO/UNICEF to ensure the accuracy and consistency of breastfeeding information given to women. It provides peer counsellor trainees with up-to-date evidence-based information on breastfeeding, together with counselling techniques for providing support. This also allows researchers to compare the efficacy of different peer counsellor programs. Systematic reviews of the evidence have found exclusive breastfeeding to be significantly prolonged with use of the WHO/ UNICEF trained peer counsellors (Kaunonen M et al, 2012; Rossman B, 2007).

Detailed training materials have been developed by Peers for Progress. These materials focus on disease specific information, communication and support skills, goal setting, linking to health care and community resources, protocols (including ethical considerations) and training approaches (including role playing) (Peers for Progress, 2018).

A key focus of any training should be ensuring that peer supporters understand their role and its parameters (Mead S et al, 2006; Fisher E et al, 2014; Embuldeniya G et al, 2013; Walker G et al, 2013; Fisher E et al, 2010; Dennis C, 2003), as well as the broader context of the peer support program (Lorig K et al, 2009). There is evidence that peer supporters should also be trained in:

- formal knowledge (i.e. autism and related subjects) (Kaunonen M et al, 2012; Dykes F et al, 2005)
- building a common language, particularly ensuring that peer supporters are talking of "experiences" (rather than using medical terminology), highlighting that each person should speak of their experience only and appreciate that others may have different experiences (Mead S et al, 2006)
- building confidence and rapport, and safeguarding the wellbeing of peers (as participants will often not feel safe or confident sharing their experiences for cultural or other personal reasons) (Peers for Progress, 2018; Dillon et al, 2013)



- basic group process skills, including delivering lectures, brainstorming, conducting structured discussions and handling difficult people (de Vries et al, 2014; Lorig et al, 2009; Dykes F et al, 2005)
- listening and communication skills, including supporting peers without judgement, creating emotional dependency or influencing their decisions (Lindsay M et al, 2017; Heisler M, 2006; Dykes F et al, 2005)
- person centred counselling skills (Heisler M, 2006; Dykes F et al, 2005)
- cultural awareness, i.e. respecting others with different cultural backgrounds, values, lifestyles and ways of storytelling (Lindsay M et al, 2017)
- evaluation principles and practices, including any evaluation framework embedded in the program (Heisler M, 2006)
- understanding and maintaining privacy and confidentiality
- collaborating and building relationships with unit staff, and recognising when to debrief or seek help from hospital staff (Lindsay M et al, 2017; Svenson G, 1998)
- record keeping and confidentiality (Dykes F et al, 2005).

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). Accordingly, training should encourage peer supporters to highlight their positive experiences. Scope (UK's) parent-to-parent peer support scheme (Face 2 Face) training involves eight sessions: non-verbal communication, body language, how to build trust in befriending relationships, boundaries and visiting procedures, keeping themselves safe and being aware of difficult feelings (Bray et al, 2017). The systematic review by Chang et al (2016) of peer support programs for autistic children, by peers without disability, found that the training approaches in the studies reviewed had a didactic component, modelling sessions, and rehearsal practices as part of the peer training. The authors concluded that peer models need structured training to help them intentionally think about, plan, and create opportunities for social interactions.

A plan should be developed for evaluating training outcomes (Peers for Progress, 2018; Svenson G, 1998). Supervision by a trainer or other staff from the program development team for the first one or two sessions may also assist to ensure peer supporters understand their roles and are providing appropriate peer support (Lindsay M et al, 2017).

#### (c) Implementation

The implementation of an effective and sustainable peer support program requires a person and family centred approach, as well as co-designed strategies and protocols for: providing ongoing support and retaining peer supporters; reaching and engaging program participants; maintaining fidelity to the structured program; and sustaining behavioural change.

#### (i) Retaining and supporting peer supporters

Early formative work should be conducted with local stakeholders to develop support strategies for peer supporters to prevent burn out and high turn-over rates (Cherrington A, 2012).

There is evidence that the experience of peer supporters can be negatively impacted by perceived isolation, lack of support and heavy caseloads (Cherrington A, 2012). They are also vulnerable from a psychological and mental health perspective if they are sharing and discussing their own challenging or traumatic experiences, or encountering difficult conversations. Accordingly, their psychosocial state should be monitored, particularly for any re-traumatisation (Meyer A et al, 2015).



There is evidence from cancer peer support studies that peer supporters who have access to support and supervision from the management team did not feel overwhelmed by their duties (Meyer A et al, 2015).

Peers for Progress outline a number of steps that can be taken, including clearly agreed roles, responsibilities and expectations from the outset, ongoing training and realistic time commitments (Peers for Progress, 2018). Characteristics of good supervision and support for peer supporters include ongoing support, regular check-ins, back up support, continuing education and on-the-job training, supportive supervision. Peer supporter input into ongoing expectations and training is also essential (peers for Progress, 2018). A strategy to respond to staff turnover should also be developed, ensuring participants are notified of staff changes (Peers for Progress, 2018).

#### (ii) Reaching and engaging program participants

As discussed above, co-designing peer support programs with community groups and participants at each stage of the program increases the likelihood that participants will remain engaged in the program (Harris J et al, 2017; Fisher E et al, 2014). Informal, varied and flexible approaches to providing peer support are also likely to maximise engagement over longer time periods (Fisher E et al, 2010).

The location/ environment, scheduling/ frequency of support must be appropriate for the participant, and not pose any barriers to their engagement (Peers for Progress, 2018; Browne et al, 2016; Fisher E et al, 2010; Dykes F et al, 2005). For example, attendance may be enhanced by having peer support on the same day as any professional sessions that may be held at the same location (Shyamasunder A et al, 2016; Dykes et al, 2005).

Protocols should be in place to support peer supporters to encourage initial and ongoing engagement by unengaged or resistant participants, without ever forcing or pressuring a participant to engage (Peers for Progress, 2018; Fisher E et al, 2010). Qualitative evidence from parents of children with dyslexia involved in a parent-to-parent peer support program highlighted that parents who felt pressured by a professional to attend the group, compared to those who initiated attendance for information and emotional support, were less satisfied with the program and did not intend to maintain regular attendance (Bull L, 2003).

The ABCRD's 2015 survey of diabetes peer support participants in Australia found that the main reasons for non-participation were being too busy and preferring to manage diabetes on their own. Among respondents who had not previously participated in peer support, the most common reason for non-participation was the perception that there were no programs relevant to their type of diabetes (Browne et al, 2016).

For low income communities, there is a need for further research into effective and sustainable, yet low-cost approaches to keeping participants engaged (Tang et al, 2014). Retention strategies, such as requesting contact information from multiple friends or family members and accommodating participant's availability for assessment, may not be adequate, yet methods such as paid taxis, conducting assessments at participant's homes or hiring staff dedicated exclusively to addressing participant retention may not be financially feasible or make a significant difference (Tang et al, 2014).

Feelings of social support and connectedness are crucial to retaining peers in peer support programs, such that there should be a continued focus by peer supporters on *initiating* communication (particularly in relation to autistic people who may have difficulty asking for support) (Siew C et al, 2017).



#### (iii) Maintaining fidelity to structured program

A systematic review of peer support interventions for autistic children by Chang Y et al (2016) highlighted that implementation fidelity (e.g. adherence, use, dose, quality of delivery etc.) was infrequently measured, but, among studies that did measure implementation fidelity, it was found to be high, ranging from 86% to 94% fidelity. Implementation fidelity was measured using a range of techniques, including checklist monitoring tools, pre- and post-training exams, rating scales and logs.

The review of literature on diabetes peer support by Dale et al (2012), similarly highlighted the value of ensuring peer supporters maintaining fidelity to the structured program (noting that with a larger population of peers this may be difficult). For telephone-based peer support, this may be best achieved through using telephone record sheets to ensure consistency of documentation regarding call content, goal setting and achievement, and length of calls. A check list of key areas covered and communication skills used has also been found to be effective (Dale et al, 2012). A program protocol may be valuable to guide peers and peer supporters, and maintain fidelity to the program (Lorig K et al, 2009).

The success of a peer support program for families with children in hospital largely was largely credited to the extent that the program had been embedded into hospital practice, with volunteers checking in with unit staff every day, before and after the visit (Lindsay M et al, 2017).

#### (iv) Sustaining behaviour change

There is limited evidence to demonstrate best practice in peer support for ensuring sustainable health improvements or behavioural change. In the mental health sector, it has been found that the positive effects of peers support may level out after six months and are not sustainable in the long term (Fuhr D et al, 2014).

For peer support models that aim to change a participant's behaviours, ongoing follow up and support are essential (Peers for Progress, 2018; Dykes F et al, 2005). This follow up and support should be integrated into the design of the peer support program, as well as any associated resources. Key features for ongoing follow up and support are available in the Peers for Progress Program Development Guide (2018), as discussed above.

#### (d) Evaluation

Robust evaluation is essential to quality program design and implementation, as well to demonstrating impact and ensuring program sustainability (Peers for Progress, 2018; Dykes F et al, 2005). However, a lack of methodological rigor and robust evaluation has limited the quality of evidence regarding peer support programs to date.

There is consistent emerging evidence that a more systematic, rigorous and robust approach to evaluation of peer support programs is required, including the following core elements: identification of evaluation model(s) at the outset; mixed-methods evaluation; realistic and holistic measures/ indicators; quality data collection; and economic evaluation.

Engagement by participants and other relevant stakeholders in the development and implementation of an evaluation model is essential.



Heisler M (2006) acknowledges that many organisations may lack significant resources for evaluation, but finds that several core elements of evaluation should be implemented, including; clear and measurable goals and objectives; adequate staff training in evaluation; targeted and streamlined data collection (via forms that are not burdensome or difficult to complete); methods of tracking progress; program inputs linked with program outputs; measurement of immediate and short-term outcomes; documented expenses (costs, including staff costs and time) and savings (benefits); and monitored and documented relationships with other clinic services.

#### (i) Identification of evaluation model at the outset

The model for evaluating the program should be determined from the outset. A range of evaluation models are available, including the RE-AIM, Logic and PRISM models (Peers for Progress, 2018).

Dykes F et al (2005) found that the most effective government-funded breastfeeding peer support programs in the UK implemented a clear evaluation strategy from the outset, which involved a continual cycle of evaluation and subsequent implementation of improvements.

Identification of the theories of change that underpin the program can support the development of the evaluation model, including specific goals and outcomes to be measured. The theories of change and evaluation framework should be shared with all peer support participants and reviewed as the intervention becomes embedded (Trickey H, 2016).

#### (ii) Mixed-methods evaluation

The weight of evidence supports mixed-methods evaluation, ideally incorporating randomized control studies and pilot interventions where feasible (Mahlke C et al, 2014). Following their review of peer support in mental health services, Mahlke C et al (2014) concluded that:

Assessing the impact of peer support on service users, peer support workers and organizations require complex intervention studies using mixed methods designs with qualitative research into process and subjective experience complementing controlled trials. High-quality research on peer support work efficacy and effectiveness should test different models of peer support work against usual care and against each other.

When collecting and evaluating data for a peer support program for parents of children with disability, Bray L et al (2017) highlighted the value of three validated self-completion questionnaires: Paediatric Inventory for Parents (PIP); Peds QL<sup>™</sup> Family Impact Module; and General Health Questionnaire-12 (GHQ-12), together with gathering qualitative data. When reviewing a specialist peer mentoring program for autistic university students, Siew C et al (2017) utilised a range of validated assessment tools to assess anxiety, feelings of social support, communication, student satisfaction and retention in autistic students accessing a university based peer support program.

There are well-conducted experimental studies of peer support on the basis of 'intention-to-treat', testing whether there was a difference between the intervention study population and the control population, regardless of whether the intervention population actually received peer support or completed the program as intended (Trickey H, 2016; Meyer A et al, 2015).



Noting the lack of methodological rigor in evaluations of HIV peer support programs, Simoni et al, 2011(b) recommended that where randomized control trials are not feasible for ethical, financial or other reasons, that at a minimum evaluation researchers: identify primary and secondary outcomes and report results for all outcomes; and provide greater specification of the measures and procedures (for example, details of how peers were elected and trained, and scope and specifics of their duty to guide further research and assist learnings to be translated to other settings) (Simoni et al, 2011(b).

Obtaining information about peers and peer supporters who drop out of a program can help program managers better understand any program weaknesses and provide more insight into matters to consider for an optimal matching of peers, training needs, supervision etc. (Meyer et al, 2015).

#### (vi) Realistic and holistic measures/indicators

Specificity about how the program is intended to work, the intermediate and long-term outcomes that are expected to result, timeframes and measurements are essential to support robust evaluation (Trickey H, 2016). For example, successful evaluations in diabetes peer support have included objectives relating to implementation, reach, engagement of and acceptance among intended audiences, initial impact on intended clinical and behavioral outcomes, and sustainability (Fisher E, 2012).

Evaluation should also seek to capture intended and unintended processes and outcomes (Trickey H, 2016). Power S et al (2010) highlights the importance of assessing potential participant needs at the outset to enable evaluators to determine whether their needs were met. Heiser M (2006) also recommends the use of measures related to participant satisfaction, reported changes in behavior, changes in health markers and resource use.

Peers for Progress (2018) have demonstrated the value of developing shared evaluation indicators. It funded eight evaluation grants to test the effectiveness of peer support in management of type 2 diabetes, with the goal of establishing a core set of shared evaluation indicators, that could be tailored to local needs (Boothroyd et al, 2010). The consensus set of shared measures developed from the Peers for Progress Evaluation grants include clinical, behavioral, quality of life, process evaluation, and mediator/ moderator (including health literacy and costs). These measures can be applied beyond diabetes management to adult health care, chronic disease management, and health promotion (Peers for Progress, 2018; Boothroyd et al, 2010).

Harris J et al (2016) recommend that peer support programs first prioritise the achievement of short or intermediate outcomes, such as initial engagement, relationship building and creation of a secure and trusting environment. The authors note that until these goals are achieved, it will be difficult to achieve any longer-term outcomes (Harris et al, 2015). Longer-term outcomes should include social process outcomes (Harris et al, 2015).

#### (v) Quality data collection

Emphasis should be placed on ensuring the collection of quality data throughout the life of the program (Peers for Progress, 2018). Guidance provided by Peers for Progress (2018) includes that it is important to consider the type of information needed for evaluation (qualitative, quantitative or both), developing a data collection plan (including data collection tools, methodology) and quality assurance for data collection (e.g. measure indicators, costs, accuracy) (Peers for Progress, 2018).



#### (vi) Economic evaluation

Where feasible, economic evaluations should also be undertaken to maximise sustainability and the likelihood of ongoing financial and political investment in the program (WHO, 2008; Peers for Progress, 2018).

Peers for Progress funded five projects to develop systematic evidence for the economic value of peer support and to address methodological challenges in the field. The resulting Economic Analysis Report finds that numerous approaches can be taken to economic evaluation, reflecting the diversity of perspectives on a wide variety of programs across different settings and populations. It emphasises that the appropriate model for any given peer support model will depend on a range of factors, including program components and local context.

Peers for Progress also highlight the importance of making a business case for a peer support program at the outset, to maximise sustainability. While recognising there is little evidence to guide the development of business cases, the authors state:

In making a business case for peer support, it is important to emphasize how peer support contributes to the quality improvement in patient care and positive return on investment (ROI) (30). Drawing attention to these benefits may cause decision-makers to change their perceptions of peer supporters from "non-essential personnel" to critical members of a team that help improve the quality of care and reduce overall health care costs.

Dr. Paula Song, along with her colleagues.... are currently examining whether existing models and tools to evaluate business cases may be applied to developing business cases for peer support programs. The team will identify both direct and incidental costs and benefits as well as non-financial considerations for peer support programs from the perspective of the organization that will be paying for the program. Specifically,

• Direct costs and benefits may include the expenditures invested in developing and implementing peer support programs, the continuing costs of operating the intervention over time, and the savings (i.e., increases in revenues or other quantifiable financial benefits that go to the organization investing in the intervention) (30, 34);

• Non-financial factors may include conditions of participation, alignment of performance incentives, organizational image, relevance to organization's mission, and impact on organizational culture (Peers for Progress, 2014).

Peers for Progress (2014) also highlights the limitations of grant funding for peer support programs, encouraging organisations to think outside the square and seek funding through other public mechanisms (it identifies opportunities through the US Affordable Care Act) or commercial entities.





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### Appendix 1: Common modes of peer support (strengths, limitations, best practice).

Peer Support Model	Structure/ implementation	Benefits	Limitations	Best practice
1. Peer support groups (face to face)	Peer support groups can differ in their purpose, structure (e.g. meeting frequency; duration of program; length of each session; drop-in versus registration; use of curriculum versus open- ended), format, and the engagement of facilitators For example, support groups can be professionally-led, use educational resources and decision-making processes to guide group discussions; peer-led, or utilise a combined approach, with professionals and peers work together to facilitate the group (Schippke J et al, 2015(b)).	Groups can provide a safe space to share experiences, offer networking opportunities and enhance self-advocacy skills (Purcal et al, 2014). Groups can be formed based on local conditions, preferences and capacities (Purcal et al, 2014) Facilitators can foster group cohesion and encourage ongoing engagement (Purcal et al, 2014) Members can act as role models to promote positives, including by disseminating success stories that inspire hope	<ul> <li>Participants may:</li> <li>be hesitant to share their personal experiences and feelings, particularly regarding sexuality (Schippke J et al, 2015(b); Meyer A et al, 2015; Shilling V et al, 2013);</li> <li>have limited time to participate, e.g. childcare; transportation; work schedules (Schippke J eta l, 2015(b); Tang et al, 2014);</li> <li>not feel a connection to the group (through a lack of similar experience or characteristics), or face conflict or criticism from the group (Dennis, 2003; Shilling V et al, 2013)</li> </ul>	Co-design with potential participants, community groups and other stakeholders (Karoff et al, 2017; Harris J et al, 2015; de Vries L, 2014; Fisher E et al, 2014). In collaboration with participants and peers, identify appropriate location, meeting times etc. (Schippke J et al, 2015(b); Dykes F, 2015). Clear criteria and procedure for recruiting peers and peer supporters, including a role description to ensure peer supporters understand their role and its parameters (Parent to Parent USA; Schippke J et al 2015(b); Peers for Progress, 2018; Mahlke, C et al, 2014; Walker G et al, 2013; WHO, 2008; Heisler M, 2006; Mead et al, 2006). Training and ongoing support for peer supporters, ideally provided through a standardized curriculum or training protocol (Mead et al, 2006; Fisher E et al, 2014; Embuldeniya G et al, 2013; Walker G et al, 2013; Fisher E et al, 2010; Dennis C, 2003) Consider appointment of a professional facilitator, recruited according to specified criteria and operating in accordance with a developed protocol (Schippke J

	and persistence (Davidson et al 2012). Participants can be		et al, 2015(b); Sartore G et al, 2013; Mead et al, 2016; Dillon J et al, 2013).
	passive or active participants.		
peer supporttechnology peers, e.g. v board, chat, meetings, o discussion, a group forum Communica involve real- (synchronou 	ia discussion e-mail, live ne-to-one and/or open b.s. tion may b.s. tion may b.s. tion may b.s. tion may b.s. tion may b.s. tion may b.s. tion may b.s. time discussion us) or reading ding to b.s. time tiss for the user b.s. tion b.s. time discussion then it is tion b.s. time discussion then it is tion b.s. time discussion then it is tion b.s. time discussion then it is tion b.s. time discussion time discussion	voice or see non-verbal	Co-design with potential participants, community groups and other stakeholders (Karoff et al, 2017; Harris J et al, 2015; de Vries L, 2014; Fisher E et al, 2014). Consider appointment of a professional facilitator, (recruited according to specified criteria and to operate) who may focus on generating and facilitating discussions (particularly in the early stages), monitoring safety, answering questions, and confirming information validity (Browne et al, 2016; Schippke J et al, 2015(b); Niela-Vilen H et al, 2014); Horgan A et al, 2013; Kaplan K et al, 2011). Require usernames and passwords to maintain confidentiality and security (Schippke J et al, 2015(b)). Provide guidelines to assist online support users to interact appropriately (e.g. typing in capital letters is considered shouting) (Schippke J et al, 2015(b)). Clear criteria and procedures for recruiting peers and peer supporters, including a role description to ensure peer supporters understand their role and its parameters (Parent to Parent USA; Schippke J et al 2015(b); Peers for Progress, 2018; Mahlke, C et al,

		through hearing of others' experiences and feeling less isolated (MacLeod A, 2010) Can enable frequent contact at low cost (Qi L et al, 2015; Cherrington A, 2012).		<ul> <li>2014; Walker G et al, 2013; WHO, 2008; Heisler M, 2006).</li> <li>Training and ongoing support for peer supporters, ideally provided through a standardised curriculum or training protocol (Mead et al, 2006; Fisher E et al, 2014; Embuldeniya G et al, 2013; Walker G et al, 2013; Fisher E et al, 2010; Dennis C, 2003)</li> <li>Clear guidelines for moderators who deliver online peer support (e.g. how to build rapport; how to interpret and reflect on discussions; how to keep participants engaged, i.e. through email notifications of new topics) (Schippke J et al, 2015(b); MacLeod A, 2010).</li> </ul>
1:1 Peer support, via peer matching.	Participants are matched with a peer with a shared experience and based on criteria to ensure the relationship meets the needs of both parents involved (Schippke J et al, 2015(b)). These programs vary in their structure and set-up depending on the context (Schippke J et al, 2015(b)).	A personal relationship can be developed, whereby peers feel safe to discuss highly personal or emotional issues (Bull, 2003) Can be informal, flexible (timing and location) and customised to the individualised needs of the participants, in an environment of their choosing (Siew et al, 2017; Karoff et al, 2017).	<ul> <li>Participants may:</li> <li>experience failed social attempts or a lack of uptake and sustainability if participants do not feel well-matched or do not engage for other reasons (e.g. differences in experiences of condition, personality) (Schippke J et al, 2015(b))</li> <li>lack a shared social identity. e.g. child's condition; parental backgrounds; language (Schippke J et al, 2015(b); Shyamasunder A et al, 2016)</li> </ul>	Co-design with potential participants, community groups and other stakeholders (Karoff et al, 2017; Harris J et al, 2015; de Vries L, 2014; Fisher E et al, 2014). Peers should be empowered to select their own peer supporter where feasible and practical. Where professionals are arranging peer matches, evidence- based criteria for the match should be established and driven by the wishes, priorities and concerns of peers. (Hoddinott P et al, 2006; Schippke J et al 2015(b)). Clear criteria and procedure for recruiting peers and peer supporters, including a role description to ensure peer supporters understand their role and its parameters (Parent to Parent USA; Schippke J et al

- have difficulty finding time to connect due to busy schedules (Schippke J et al, 2015(b))
- experience emotional overinvolvement resulting in contagion stress (Dennis C, 2003)
- fail to understand the parameters of peer support, i.e. sharing of experiences, not professional/ therapy support (Dennis C, 2003)
- find interactions to be personally intense, and feel pressured to follow advice (Hoddinott P et al, 2006).

The detailed matching of peers and participants can be time consuming and may not be practical or possible in everyday practice (Dale et al, 2012). 2015(b); Peers for Progress, 2018; Mahlke, C et al, 2014; Walker G et al, 2013; WHO, 2008; Heisler M, 2006).

Training and ongoing support for peer supporters, ideally provided through a standardized curriculum or training protocol (Mead et al, 2006; Fisher E et al, 2014; Embuldeniya G et al, 2013; Walker G et al, 2013; Fisher E et al, 2010; Dennis C, 2003)

Relationship should continue to be monitored through follow up with both participants, to ensure mutual satisfaction and provide an opportunity to offer support and/or additional resources (or re match if necessary) (Parent to Parent USA 2017).

Oversight and support from a professional to address any difficulties, mental health impacts or other deleterious effects of peer matching (Schippke J et al, 2015(b)); Dillon J et al, 2013).