Quick Guide

Online NDIS Peer Support Networks

Introduction

This Quick Guide gives information that can help a person start or join an online peer network.

Online peer support is when people in similar situations and with similar experiences share knowledge and help each other, all online. These forums provide a community where people can get together, ask questions, share what's going on and also 'vent' or just connect.

Online peer support is attractive because it's anonymous and convenient; it is there whenever a person is available. It can provide a sense of belonging, a sense of openness without judgement and it is also cost effective, free for the user, and instantaneous.

This Quick Guide looks at how a peer network might set up an online forum or inform its members about an online group and some of the issues to be aware of.

Let's make it happen

There has been a growth in online peer networks within the disability sector as people view them as an accessible, and non-threatening alternative to conventional support groups. There can be open and closed groups and usually they require an administrator or moderator to help ensure that the network is being utilised appropriately and people are being respectful of each other.

In the next section, this Quick Guide provides links to a number of online peer networks in regard to the NDIS. Most of these are Facebook groups.

Facebook Groups

A Facebook group is a page created for an organization or business to promote activities. Users can join the group and post their thoughts on a wall and interact through discussion threads.

Facebook Groups "allow people to come together around a common cause, issue or activity to organize, express objectives, discuss issues, post photos and share related content."[1] Facebook pages can be public (open), closed or secret. This website blog defines them as:

> *A public group is exactly what it sounds like. It's fully visible to everyone, and anyone can join without being approved. All members' posts are fully visible to all other Facebook users, so this type of group does not offer the sense of privacy and security that comes with the more restricted group types. However, it is the easiest group type for users to join, and can therefore grow quickly.*

> *In a closed group, posts are only visible to members, so there's a sense of being involved in an exclusive community. The group itself appears in Facebook searches, and the description and member list are visible to anyone on Facebook. It doesn't offer complete privacy, but members can feel comfortable knowing that the posts they share are visible only to members of the group. All new membership requests must be approved by an existing member or administrator of the group.*

> *A secret group offers the same post privacy as a closed group, with an added level of stealth: the group does not show up in Facebook searches. The only way to find and join a secret group is to be invited by an existing member.*

The best Facebook groups have a high level of engagement and regular interaction going on. The group members are very active in either starting discussions or taking part in them in one way or another. The key is to start a Facebook group with a common interest.

The posts made in a group don't go to the newsfeed. Instead a notification is sent to each member (depending on their notification settings) letting them know that a new post has been posted within the group. This is beneficial in the sense that the members won't miss out on a post.[2]

If setting up a group, you'll have to establish clear rules for your members and make sure that they are being followed. As the group grows, this can become more and more difficult. This will mean that the group may take a lot more of your time. For a good group to thrive, the leader needs to be as active as, if not more than, its members.

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[1] https://https://blog.hootsuite.com/facebook-groups-business/
[2] http://www.vanessa-cabrera.com/pros-cons-facebook-page-vs-facebook-group-business/

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As the leader, you'll need to engage your members, answer questions, monitor possible disputes, which again can become very time consuming.

Pros and Cons

There are pros and cons with being part of or starting a Facebook group. There are considerations over whether a group is closed or open. Adaptivateblog.com describes the pros and cons as:

Open Group

Pros: Open groups don't require a staff member or volunteer to approve individual requests to join. A potential member need only click the "add me to this group" link and they're in. There are fewer barriers to entry for this type of group. Additionally, you have the potential benefit of many more points of view and input from a wide variety of users.
Depending on the purpose of the group, open membership may be a good fit; if the group is meant to discuss a general topic or casts a wide net over a certain subject, open membership may be the best option.

Cons: Open groups can easily swell in size and become unwieldy. These types of groups can be magnets for people who want to join as many groups as possible, but don't necessarily have useful points of view or information to share (read: salespeople and spammers). Once they clutter discussion boards and dominate conversations, your group may be rendered useless, and legitimate members will abandon ship.

Closed Group

Pros: Closed groups require a trusted individual (generally a staff member or a volunteer) to approve individual membership requests.
Closed groups provide members with a sense of legitimacy: they know that the people in the group have gone through an approval process. A good example of a type of group that can benefit from closed membership is an alumni group. It provides assurance to members that everyone in the group 'belongs.'

Closed groups also keep a damper on spammers – those who rack up group memberships with the intent to sell products won't make it through the sieve (unless they happen to have a legitimate reason to be a member of the group, of course).

Cons: Maintaining a closed group requires careful management. Someone (staff, volunteer or otherwise) has to make sure that each member request is legit…and that eats up time. It also adds an additional hoop to jump through, which may be a turn off to potential group members; someone who has to wait too long in membership purgatory may grow frustrated and withdraw their request.[3]

Cyber-safety

While Facebook groups can provide an excellent avenue for peer support, it is important to note that it can also be a place where people may express extreme and offensive views and/or anger and you may encounter cyber-bullying.

It is therefore important that everyone knows how to be safe and recognise behaviour that is counterproductive to the group's intentions.

This website provides examples of what cyber-bullying looks like and what tactics are used.

https://www.opencolleges.edu.au/informed/cyber-safety/

The Australian Federal Police have also developed a website http://www.thinkuknow.org.au/which, while aimed at children and young people, also looks at cyber safety.

It can be beneficial to a conventional peer network (who meet face-to-face) if some of their members join an online group as this can bring in new and different information that can be used in all peer network meetings.

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[3] https://adaptivateblog.com/2009/09/08/open-group-closed-group/

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Where you can find more information

This part of the Quick Guide provides information about the various Facebook groups on the basis that we know the group exists but we are not necessarily members and so we don't know much detail about how the group operates.

Each peer network member will need to do their own research and find out what works for them. It is fairly easy to leave a group if it does not work out.

It is also worth thinking about the number of groups you join as having too many will inundate your timeline and won't leave enough time for thoughtful and beneficial interaction and discussion.

NDIS related Facebook Groups

NDIS National Insurance Scheme

This is the official NDIS facebook page

https://www.facebook.com/NDISAus/

NDIS Grassroots Discussion

A group for people with disabilities, family members and supporters to discuss the National Disability Insurance Scheme (NDIS) and what we need from it to live full lives.

https://www.facebook.com/search/top/?q=ndis%20grassroots%20discussion

NDIS Discussion Group

https://www.facebook.com/groups/120451141819700/

NDIS Chinese Discussion Group

https://www.facebook.com/NDIS.Chinese/

NDIS Matters

A place to ask your NDIS questions.

https://www.facebook.com/groups/1135707456551460/

I LOVE NDIS

This group is a team made up of people who have a positive outlook on NDIS. It is a place to ask questions, offer advice and share your positive experiences with NDIS.

https://www.facebook.com/groups/376325766041728/

NDIS find-a-housemate

This group is set up to help people find NDIS housemates. You don't have to have a disability to express an interest.

https://www.facebook.com/groups/NDIS.find.a.housemate/

NDIS Self-Managing Participants and Their Families

NDIS self management is a wonderful chance for people to have more control, and to reduce the impact of disability on their lives. This is a peer led group. That means we are all on the same journey, self managing our funding, or that of a family member. The purpose of this group is for participants and families to crowd source information that is directly related to self-managing, by sharing experiences and asking questions.

https://www.facebook.com/groups/896104837175411/

NDIS School Aged Families in SA

ForPrimary and high school School Aged NDIS FAMILIES in SA only

https://www.facebook.com/groups/NDISSchoolAgedFamilies/

Autism NDIS Support

An Australian support group for people who care for or are on the Autism Spectrum and are navigating the NDIS.

https://www.facebook.com/groups/AutismNDISsupport/

NDIS and Me

a Facebook group for Australians with Down syndrome and their families. The group aims to help its members to get ready and get the best outcomes they can from the National Disability Insurance Scheme

https://www.facebook.com/groups/NDISandMe/

NDIS People with physical disabilities

This group has been set up for people with physical disabilities as a safe place to discuss their NDIS journeys

https://www.facebook.com/groups/128412471169083/

NDIS for Aboriginal Families

This is a private group for Aboriginal families to understand and get the best out of the NDIS. Share stories, tips on planning, pre planning and funding management.

https://www.facebook.com/groups/181267539155508/

NDIS CoS & Plan Managers Unite

A group specifically for Support Coordinators and Plan Managers, for sharing ideas, asking questions etc

https://www.facebook.com/groups/442386536130373/

The Carers Couch – NDIS Discussion

Support group for carers to share information and be suportive and to learn about but not limited to NDIS. There will be sharing of useful information, links on meetings and workshops as well as facebook live events and coffee catch up

https://www.facebook.com/groups/791031951037133/

Mental Health and the NDIS – Australia

This sister group was created to allow NDIS workers and services providers, and also those who are apart of this community group as well safe place for to be able to access support and gain knowledge to help support their own journeys

https://www.facebook.com/groups/1648487538786168/

NDIS (not Damn Interested In Seniors). = My Aged Scare

Our campaign group aims to provide up-to-date information about the support options available to older people with disability, and advocate for equality of support for those older people with disability who fall outside the NDIS.

https://www.facebook.com/groups/99107248763942/about/

Assistance Dogs and the NDIS

A support group for people with assistance dogs who are applying for NDIS funding in Australia.

https://www.facebook.com/groups/161017424430403/

This blog *Everything you need to know about Facebook Groups* details how to create a Facebook group

It also explains how to search for groups that may interest you by using the search engine and key words

https://blog.hootsuite.com/facebook-groups-business/

This article talks about the pros and cons of running a facebook group

https://www.ptdistinction.com/blog/running-your-own-facebook-group-the-pros-and-cons