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Peer Support Guide

For Parents of Children or Youth with Mental Health Problems



Strengthening Family and Youth Voices Project

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Peer Support Guide For Parents of Children or Youth with Mental Health Problems

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Peer Support Guide

For Parents of Children or Youth with Mental Health Problems

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Disclaimer

The information contained in this guide was written to act as a guide for parent leaders in providing peer support and mutual aid to other parents with children and youth with mental health problems.

Parent-to-parent support groups are not a substitute for mental health advice or opinion from qualified mental health practitioners.



Introduction

The purpose of this guide is to provide a starting point for parents wishing to develop peer support for other parents of children or youth with mental health problems. Here you will find practical information and resources on the ways in which parents can learn from and support each other in a group setting, and how to organize and develop your own parent peer support group.

Though the term parent is used throughout this guide, it is intended to represent any caregivers of children and youth.

Background

The Canadian Mental Health Association, BC Division (www.cmha.bc.ca) was funded by the Public Health Agency of Canada to complete a two-year project called Strengthening Family and Youth Voices.

The project goals were:

- To promote the participation in decision-making of families and youth who use child and youth mental health services
- To increase peer support networks across five pilot sites

To support the project, the Ministry of Children & Family Development (www.gov.bc.ca/mcf) contracted The FORCE Society for Kids' Mental Health (www.bckidsmentalhealth.org) to provide support to the project, particularly in the development of parent support groups.

In turn, the Canadian Mental Health Association, BC Division contracted The FORCE to create this guide as one way to support parent peer support in the child and youth mental health sector.

The FORCE is a non-profit society formed by five mothers in 1999 to promote and influence change in early intervention, treatment and equality of care in children's mental health.



What is Peer Support?

For the purpose of this guide, we are excerpting from the Self Help Resource Association of BC's website (www.selfhelpresource.bc.ca), which defines peer support as:

- People who share a common problem, challenge or issue learning from and providing support to one another
- Opportunities to learn new coping skills and new means to approach or improve their personal situations
- Something that can be done one-on-one or in groups, in person, by telephone or online
- Unique, offering the kind of support that one can only get from others who share similar experiences



A parent support group is a group of parents who come together to share experiences and to gain strength, hope and new ideas from each other.

Elements of a self-help group:

- Members and facilitators share the same problems or have had similar experiences
- Members set meeting details
- Tasks are shared among members—all members are volunteers
- Groups may be either open or closed to new members once the meetings have begun
- Pre-registration usually not required
- Group decides goals and agenda and may follow the needs of a particular member as issues arise
- No fee, or minimal fee to cover costs



What Parents Can Offer Parents

Many parents find that in addition to support and services they receive from qualified mental health professionals, they wish that they could talk to another parent who has had similar experiences. When asked who is best able to support them emotionally, parents often identify other parents who can share their experiences.

Parents can provide the following to other parents:

Acceptance

For many parents, there has been at least one occasion where the parent has felt blamed or responsible because of the emotional and behavioral challenges their child is experiencing. It is often only other parents who are living with the same challenges that can truly make another parent feel accepted despite the difficulties they are experiencing.

Sense of Belonging

For many parents, once they begin to share their experiences with other parents of children with mental health problems, they see that others 'get it' and they develop a sense of belonging that they may not have experienced before with other parents.

Understanding

Many parents may not get the kind of support and understanding from family and friends that they have gotten in the past for other challenges they have faced. This can sometimes come from other people's lack of understanding of the situation, or their fear of what they are seeing happening to your child and your family. Parents in peer support often get a sense of relief because they don't have to explain why their child is behaving the way they are or why, as parents of this child, you are tired all the time. The other parents just 'get it.'

Marital Support

For many parents, keeping their marriage strong is a real challenge given the strain and stress that comes with having a child with mental health problems. Parents often have no place to talk about these issues or to hear that others are experiencing the same challenges. Peer support groups can provide a space to share these experiences.

Information

Many parents benefit from sharing information with other parents. A lot of useful information can be exchanged. For example, you might join a peer support group if you want to:

- ◆ talk to someone about the impact of mental health problems on your child, family and friends
- ◆ discuss the stress of dealing with multiple doctors, learning a whole new vocabulary, and dealing with the financial aspects of mental health problems
- ◆ find support and advice about special classes and services, about how to talk to educators about your child's difficulties, and how to remain optimistic
- ◆ learn tips from other parents on how they have managed similar challenges
- ◆ develop confidence in your own ideas and impressions about what your child needs and wants.

Time for Yourself

For many parents, having a child with mental health problems often means that there is very little time or resources available for parents themselves. Over a long period of time, it can become hard to pull back and allow some time for yourself. This can lead to burnout. A peer support group can help parents gain perspective and provide them with help and support.

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Getting Started

This section is divided into three parts: steps to consider before launching the peer support group, steps to consider for the first meeting and steps to consider for the second meeting. Each part includes a brief description of the key steps with additional materials included in the appendices.

Pre-Launch Preparations

These suggestions are meant to act as guides and options for your consideration when looking at launching a parent peer support group. You are encouraged to add to or change the suggestions in order to meet your group's needs. A pre-launch checklist can be found in Appendix A.

Step 1 | Check Out Existing Parent Groups

There are often parent support groups offered in a community, and you can get valuable information by finding out what is available and talking to parent facilitators. These contacts can help in a number of ways, including:

- Making sure that you are not starting something that already exists
- Providing a source of information to parents who do participate in your group who may require different or additional supports
- Getting suggestions for starting up your own group and finding possible partners in the community

Step 2 | Identify a Co-facilitator for the Group

It's very helpful to find at least one other parent who shares an interest in supporting parents in a peer support group format. Finding this person may take some time, but it is time well spent as it will strengthen your group and support you in getting the group going and keeping it going.

While looking for a co-facilitator also take the time to look for other parents who may want to be members of the group and who may also have time to help. The most important thing is to find people with whom you feel comfortable.

Facilitating a peer support group can be both rewarding and challenging. It is important to consider the kinds of skills and abilities that effective facilitators bring to peer support. The Self Help Resource Association of BC has a series of training manuals available on their website at www.selfhelpresource.bc.ca that can help you and your co-facilitator reflect on the relevant skills that you each will bring to the group as well as those you may want to develop or strengthen. These manuals include:

- Basic Skills
- Communication and Assertiveness Skills
- Facilitation Skills
- Conflict Resolution and Collaborative Problem-Solving Skills

Step 3 | Identify Common Goals for the Group with your Co-facilitator

It is important to have a discussion with your co-facilitator ahead of the first meeting to determine common goals and what your roles will be in organizing, facilitating and developing the group.

Step 4 | Identify Community Partners

Families will also often seek treatment and support from local mental health agencies and service providers and it's worth asking those people if they can support the group by providing meeting space, guest speakers or through promotion of the group.

Step 5 | Meeting Details**Place to Meet**

The setting for meetings is very important. The following should be considered: comfortable atmosphere, parking, convenience by public transportation, and accessibility.

Date & Time

The day and time of the first meeting can be set by the facilitators, but subsequent meeting schedule should be decided by the group members.

Refreshments

Food and drinks are a way to create an inviting, informal tone and it's worth seeing if you can get these items donated.

Babysitting

Parents are often restricted from attending parent support groups due to childcare challenges. Check with your local school, community centre or other family-serving agencies to see if they can offer any help with childcare during your meeting.

Supplies

Ask if the organization providing meeting space can also provide a flip chart and markers for recording discussion points from your group meeting.

Step 6 | Promotion of Group

Promoting the group for the first and subsequent meetings is very important. Some promotional ideas to consider include:

Flyers

Develop a simple invitation flyer and post it in any places that parents frequent including schools, community centres and service provider offices. A sample invitation flyer can be found in Appendix B.

Community Partners

Invite mental health service providers, school counsellors and other community partners to promote the group to any parents they know who might be interested.

Media

Often there is interest at the community newspaper for human interest stories where you can also promote the creation of a new group for parents. The local cable channel or radio station may also have ways to promote the first and ongoing meetings.

First Meeting

The first meeting is an important one to begin to set the tone of the group. Don't worry about numbers—it's more important to connect to the parents who do attend. Some of the steps to consider are outlined below. A sample first meeting agenda can be found in Appendix C.



Providing refreshments will help the parents feel welcome and is often a comfortable place to greet each other and socialize before the group meeting begins.

Step 1 | Set Up

Bring a sign-up sheet, an agenda and any other resources you will be using for the first meeting. It is important to make the room welcoming and ensure that refreshments are out and ready. If the room is hard to find, make sure you post signs directing people to the meeting.

Step 2 | Greet Parents

It's a good idea to introduce yourself at the door so the parents know who has arranged the group and they feel welcomed.

Step 4 | Share Your Story

A lot of parents will be a little nervous or reluctant at a first meeting, so it's really helpful to open the conversation by sharing a bit about yourself and what you bring to the group, as well as your goals for the group. It is important to briefly discuss confidentiality at this point—for example, that group members' names will not leave the room—although you may want to wait for the second meeting to establish overall group rules.

Confidentiality can be one of the most important things in a peer support group, even more so if the community is small. People often share personal stories that can be very sad or upsetting, and it usually takes a lot of trust for people to open up to strangers. It is very important to respect this trust and ask group members to keep all information and stories shared during the meetings in confidence.

Step 5 | Discuss Barriers to Attending Support Groups

It is important to understand and discuss with the group some of the challenges and feelings parents have in attending support groups. Barriers may include:

- Stigma of mental health problems
- No one else to stay with the child or youth or their siblings
- Too burned out to venture out to another meeting
- Nervous about what might happen at a group

It is important to acknowledge these challenges and identify how you as a group will try to address them.

Step 6 | Encourage Sharing

Sharing with the group provides a common ground on which people can start to identify with others and trust that they are not alone in their challenges. It can also demonstrate that everyone isn't necessarily there for the same reason. For the first while, people may say they just want to hear from other parents. It may take some time for the group to become comfortable speaking about other needs they have.

Step 7 | Identify Common Experiences

There may be quite a range of challenges that bring parents to the group and it is important to try to identify the most prevalent and common experiences of the group so that parents feel connected on various levels with each other.

Step 8 | Provide a Sign-Up Sheet

The sign-up sheet allows for the facilitator to contact parents on the list with future meeting information and general information. Parents may not feel comfortable putting their name down the first time, so it's important to let them know they don't have to. A sample sign-up sheet is provided in Appendix D.

Step 9 | Discuss Meeting Times

Some members may wish to meet more often or request that meetings change to a different time or location, or just to meet for coffee outside of meetings. It is important to have parents be part of the decision-making process on things concerning the group. It's also good to periodically bring up the topic of meeting times to get parents' input.

Step 10 | Discuss Meeting Format

There are many different forms that a support group can take and it's important to discuss and define what the group would like. One popular option is alternating between meetings focused on parent-sharing, and educational meetings on a particular topic with a guest speaker or other way of providing education/information. This can be discussed at the first meeting and then revisited at future meetings.

• • • • • • • • • •

Try offering an education or information night on a particular topic, to reach out to new members and create awareness about your support group.

Step 11 | Identify Communication needs

It's important to have the group members identify how they would like to receive information. Email is most time-efficient, but some parents may prefer a phone call instead so it's important to have this option available. Preferred method of contact can be included on the sign-up sheet.

At the end of the first meeting, if you haven't already done so, let the group know that there are important group guidelines that will need to be discussed at the beginning of the next meeting.

Step 12 | Meeting Closure

It is often helpful to go around the group to see if anyone would like to say anything, or if there was something in particular that they gained from the group meeting that was especially meaningful or that they were grateful for.

Second Meeting

In addition to other regular agenda items, this meeting will include a discussion of group guidelines. Group guidelines are important as they set out how people are expected to behave with one another in order for the group to run more effectively for everyone.

Step 1 | Discuss Guidelines

The following are some guidelines excerpted from the *Parent-to-Parent Support Manual for Group Members*, which provide an excellent starting place for the group discussion.¹

• • • • •
Remind members that participants are not mental health professionals and support groups are not a substitute for the services of a professional.

- Respect each other's different opinions, experiences and situations
- Allow each person to speak without interruption
- Keep what is discussed at the group meetings confidential. This means: "what you see here, what you hear here, when you leave here, let it stay here."
- Note that there are two exceptions to group confidentiality, outlined to the right
- Try to arrive on time
- Share responsibility by taking turns in various roles such as coffee-maker or facilitator
- Contribute what you can for the expenses, if applicable

Exceptions to Confidentiality

There are two exceptions to confidentiality which should be discussed by your group:

- 1) If you have reason to believe that a child or youth needs protection.
- 2) If someone in the group states they have plans to harm themselves or someone else.

The agreed-upon rules or guidelines can then be written down and referred to from time to time within the group.

Step 2 | How to Be a Good Group Member

At this point in the discussion it may make sense to review the hand-out, *How to Be a Good Group Member*, found in Appendix E.

Step 3 | Sharing Responsibilities

Because you want to guard against 'burnout' and share the responsibilities in a peer support group, one way to identify and clarify roles is to create a volunteer sign-up sheet. It's good to create this list with your group and remind them that they will only be asked to do something if they can and are comfortable doing it...no pressure! A sample volunteer sign-up sheet is provided in Appendix F.

Step 4 | Topics and Speakers

Have parents share what topics or speakers they would find meaningful and record it in a speaker log. A sample speaker log is provided in Appendix G.

Possible group or speaker topics could include:

- Working with professionals: benefits and challenges
- Impact of child and youth mental health problems on families
- Grief and stages of grief
- Dealing with contentious issues



Suggestions for Future Meetings

There are many approaches to building-in new elements to peer support groups. Your group may want to explore some or all of the suggestions below, or may want to develop the group's own ideas. In any case, the following are meant to provide facilitators with something in their 'back pocket' that they can pull out as the group continues to meet.

Online Group Discussions

Ask the group if anyone is interested in developing an online group discussion where families can share ideas, thoughts and support with each other at an agreed-upon time. If there is sufficient interest, identify a volunteer who is willing to organize the discussion.

PeerNetBC (www.peernetbc.com) is a British Columbia-based online community for self-help and peer support. PeerNetBC is designed to support and connect people online by offering everything from free group discussion space for self-help and peer support groups, to tips and resources on online support group facilitation and participation.

Resource Binder Night

One of the benefits of a support group is sharing both experiences and resources. Ask parents to bring or suggest things that they have found helpful that they would like to share with the group. As a group facilitator, arrange to have copies of magazine or journal articles, brochures, or other helpful resources to share with parents.

A resource binder night can be a particular meeting when the group agrees to develop their own binders of information. The following outlines some of the steps required:

- Purchase a four-ring binder in which to collect photocopies of shared resources
- Put a disclaimer in the front of the binder. For a sample disclaimer see Appendix H
- Create an index table for recording a list of binder contents
- Use dividers to organize and label different categories
- Suggest that parents bring their own binder, but purchase enough dividers and labels to put together a package for each parent
- Provide enough copies of information for each person to put into their own binder
- Ask parents to bring enough copies of information they bring for each of the other members

Some categories that you might want to include:

- Types of mental health problems in children and youth
- Community resources
- School information
- Medication
- Alternative treatments
- Articles of interest
- Research
- Book lists
- Parent education

Starting a Book Club

- Start by finding a book that most or some parents are interested in, and have everyone agree to purchase the book
- Assign one or two chapters for everyone to read and ask them to come to the next meeting prepared to discuss what was read
- Any new people joining the group should be advised of the book that is being discussed so that they may choose to participate
- Look into having the author of the book as a speaker or speak to local agencies or service providers about having the author brought in for the community

Creating a Library

You can create a group library by having families bring in books, magazines, DVDs and other resources that they have found helpful in dealing with their family's challenges.

You will need a volunteer to run the library. The volunteer will probably need to purchase a large plastic container and trolley to transport the books back and forth to each meeting. Their other responsibilities will be to:

- Explain to parents how the library works
- Keep track of library inventory. A sample library inventory sheet is provided in Appendix I
- Ensure parents are signing out books and checking off when they return them. For a sample library sign-out sample sheet, see Appendix J
- Make sure parents pay a \$10 deposit before they take books out, and refund their money upon return of the resource
- Phone parents at the end of year if resources are not returned
- Plan on coming to meetings 15 minutes early to set up books and staying 15 minutes after meetings to help parents sign out books and pack up remaining books



Stages of Group Development

There are fairly predictable stages of group development. The following section outlines key stages experienced by many peer support groups.

Stage 1 | In the beginning

Parents are sometimes very unsure or nervous about what the group is all about, and they may start by saying that they have to leave early. This stage can sometimes take a few months as people become more comfortable with the group and familiar with what the group is about.

Stage 2 | Less unsure but still checking it out

Parents will often keep attending the group to see what else it might have to offer, even though they aren't quite ready to commit fully. Sometimes they will also want to observe other people and try to determine the personalities and roles of other parents in the group. As people feel each other out and power relationships are explored, conflict can arise in the group. It is important to ensure that the group has some rules or guidelines by this point to ensure everyone feels heard and respected.

Stage 3 | I'm in

Parents at this stage are regular members and have given their commitment to the group. This can take up to a year, so patience is required in establishing successful peer support groups. There also may not be as many members at this stage, but there will probably be a core group.

Stage 4 | This may not be for me anymore

Due to various reasons, some parents will no longer need or want to continue with a group. However, it is important to keep the group going even with very few members, as people often drop out but will drop back in later or refer another parent who is in need. The group facilitator may also change during this time so it's important to always have members who are trained to take over the facilitator's role if necessary. Sometimes groups at this point will return to the 'in the beginning' stage of group development.



Group Momentum

Building and sustaining group momentum can be a challenge. The first step in building momentum is making sure that the group is working well for the current group members. In order to do this, it's helpful to build-in opportunities for parents to provide feedback about things that are working well for them, things that are not working as well, as well as their suggestions for change. Suggestions for group evaluation and sample evaluation questions are provided in Appendix K. However you collect parent feedback, it is important that the feedback is confidential to ensure that parents feel comfortable to identify areas for improvement.

It is also important to remember that groups ebb and flow. Some parents will continue to meet regularly while others may attend from time-to-time.

The following are some suggestions for sustaining group momentum:

- Ask parents to reach out to other parents and find out where they heard about the group, to see if there are any obvious 'best' ways to let others know.
- Ask service providers if they could let parents know about your group. Having a summary of parent evaluations can be very helpful in presenting the benefits of the group to service providers. Another option is to ask service providers if some of the parents could speak to them about what they are getting from the group and how the group operates.
- Ensure you have up-to-date signs made that are posted in key places throughout your community. Provide the time, date and location of meetings, as well as a contact number.

Need More Tips?

The Self Help Resource Association of BC has a number of short, practical guides for peer support groups available in the information and resources section of their website at www.selfhelpresource.bc.ca, including:

- Managing a Crisis in a Self-Help Group
- Self-Help in Rural Communities: Similarities and Differences
- Self-Help and Professionals: A Practical Alliance
- Six Steps to Start a Successful Self-Help/Peer Support Group

Another helpful resource is PeerNetBC (www.peernetbc.com), an online community for self-help and peer support networks recently launched by the Self Help Resource Association of BC.

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Appendices

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Pre-Launch Checklist

Task	Date	Person Responsible	Outcomes
Check out other parent groups			
Identify parent co-facilitator			
Define goals for forming a parent peer support group			
Identify community partners			
Find a place to meet			
Create invitation flyer (See Appendix B)			
Distribute flyer			
Other promotion activities			
Contact media			
Arrange for babysitting			
Purchase snacks and drinks			
Arrange to have a flip chart and markers			



Parent Support Group

For Parents of Children or Youth with Mental Health Problems

Initial Meeting Date:

Time:

Location:

Interested in meeting other parents who are struggling to understand and support their kids with mental health problems?

Please Join Us!

For more information, please contact:

Agenda

Date:

- 1) Welcome
- 2) Co-facilitators' introductions
 - Co-facilitators' stories
 - Co-facilitators' goals
 - Confidentiality
 - Barriers to attending support groups
- 3) Parent sharing
- 4) Identify things in common
- 5) Sign-up sheet
- 6) Meeting times and date
- 7) Meeting format
- 8) Next Meeting
- 9) Meeting Closure

15 minutes will be given at the end of the group meeting for informal chat.

How to Be a Good Group Member

1 **Keep what is said in the group confidential**

A major concern for some members is having their privacy respected. Be clear about what confidentiality means for the group. Members should not be talked about in any identifiable way outside the group.

2 **Ask people if they want advice or a suggestion before you give it**

For many people, as soon as they hear a problem they have a tendency to start thinking about how to 'fix it.' However, sometimes people just need to say how they feel and aren't ready to start thinking about how to deal with the problem. Another thing to keep in mind is that one person's 'solutions' may not work for someone else.

3 **Know that some parents can be very intense and goal-oriented**

At times, you may want to criticize or disagree with treatments or services other parents are seeking for their children. Remember that no one has the right to judge for another parent what kind of treatment or service he or she needs to pursue. However, if there is a question of any neglect, malpractice or abuse, professional advice must be sought.

4 **Understand that people in the group will be at different stages**

For those who are still coping with the feelings of helplessness that often accompany the diagnosis of a child with a mental health problem, remember that they need to feel listened to and understood. They often feel worse when someone says, "cheer up." Parents who are in the next stage of searching for answers may impress you, intimidate you or perhaps inspire you with their energy and exhausting schedules.

5 **Expect that you may not always get a chance to talk as much as you want**

If you tend to be a quiet person, you may feel uncomfortable about speaking out in the group at first. If you want to talk about a problem or raise an issue, you may have to be very assertive and announce that you need a few minutes to talk about a problem.

6 **Realize that you don't have to like everyone in the group**

You don't need to share the same philosophy of life. You also don't need to have the same level of education or income.

7 **Realize that peer support groups cannot solve personal problems**

Sometimes they can help you to clarify problems and find out where to get further help. Many problems about your child can't be solved in the group. For instance, if your child has a severe behaviour problem, the group leaders or other members may be able to offer suggestions, support or empathy, but you may also need to seek professional help outside the group.

Volunteer Sign-Up

	Set-Up Person	Clean-Up Person
Duties	Helps set up refreshments and the room. Needs to arrive ½ hour before meeting.	Helps clean up, wash dishes and tidy room. Needs to stay ½ hour after meeting
January		
February		
March		
April		
May		
June		
July		
August		
September		
October		
November		
December		

Appendix H | Sample Binder Disclaimer

Disclaimer

This binder of photocopied information has been an accumulation of shared information from parents attending the support group meetings. One of the support group's main objectives is to inform parents on all kinds of information that is relevant to our children's needs. The support group does not endorse, support or recommend any particular method, resource, product or treatment for your child(ren).

Information provided is not a substitute for professional advice. If you feel that you need medical advice, please consult a qualified health care professional.

Sample Evaluation Questions

You may choose to use some or all of the questions below, or you may choose to add some new questions. You can develop evaluation forms for people to complete on paper, or web surveys for people to complete online. Survey Monkey (www.surveymonkey.com) is a free online resource you can use to make simple web surveys.

Depending on the size of the group, some of the questions below might reduce the level of confidentiality of the survey (for instance, if only one person has been part of the group longer than 12 months), in which case those questions should not be used.

- 1) How long have you been involved in the support group?
 - 1-2 months
 - 3-5 months
 - 6-8 months
 - 9-12 months
 - more than one year
- 2) How did you hear about the group?
 - Friend
 - Caregiver
 - Service Provider
 - Flyer
 - Media _____
 - Other _____
- 3) What did you like about this group?
- 4) What did you not like about the group?
- 5) What could have increased your participation in the group?
- 6) Does your group welcome feedback? (yes/no)
Please specify.
- 7) Why did you join this group?
- 8) Has participation in the group provided you with emotional support to cope better with your child/youth's mental health problems? (yes/no)
If yes, please describe.
- 9) Has participation in the group provided you with concrete skills to better manage your child/youth's mental health problems? (yes/no)
If yes, please describe.
- 10) As part of the group, have you learned ways to manage your own stress? (yes/no)
If yes, please describe.
- 11) Did the group identify resources or services that were helpful to you? (yes/no)
If yes, please describe the resources.
- 12) Since I joined the group, I am more confident about my understanding of mental health problems in youth.
 - Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
 - No change

- 13) Since I joined the group I am more confident about my ability to support my child/youth's mental health problems at home.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
 - No change
- 14) Since I joined the group, I feel more confident to participate in the formal care (doctors, teachers, etc.) of my child/youth's mental health problems.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
 - No change



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