



Guidelines for setting up Parents Self-Help Groups

A Guide for Member Organisations
and Parents of Persons with
Intellectual Disability

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1. Introduction

Inclusion Ghana (IG), a member of Inclusion International, is a network organisation working to reduce stigmatization and ensure full inclusion of all persons with intellectual disability (PWIDs) and their families by advocating for their rights and needs. IG envisions equal opportunities and inclusion for all persons with intellectual disability in Ghana.

We believe there is a need to empower, motivate and support parents, through our member organisations. Parents of PWIDs are often confronted with stigmatization and discrimination because of their children's disability. By forming Parents Self- Help Groups (PSHGs), parents will have a platform to meet people with the same circumstances with whom they can exchange their experiences and emotions. Together parents can support each other as they learn how to cope with these difficulties and gather tools and knowledge that can be helpful in their lives and those of their children.

Due to the stigmatisation attached to intellectual disability in Ghana, many families find it difficult to talk openly about their situation and more importantly to access the range of services available. Inclusion Ghana encourages Member Organisations to work with the parents of PWIDs in their communities to form Parent Self-Help Groups which can serve as platforms to share experiences and to build knowledge about living with PWIDs.

PSHGs aim to empower parents of PWIDs against stigmatisation and exclusion from society.

2. What are the Parents Self-Help Groups (PSHGs) about?

Parents are the focus of PSHGs, not their children. Parents need to be strong to be able to take care of their children. When parents are empowered, it is then that their children have possibilities. A parent can only help a child when she herself is strong.

The PSHG is about parents of children with intellectual disabilities coming together to share experiences, difficulties, and successes. These parents should be drawn together by a common background, exclusion and isolation from their families and society as a result of their disabled children.

The Parents Self-help group will offer parents the opportunity to meet with other parents and to share their experiences, knowledge, strengths and hopes. Parent participants will support each other as they cope with the stigmatisation of their children and themselves by sharing experiences or by advocating and lobbying against this stigmatisation.

2.1 Characteristics of Parents Self-Help Groups

■ Common Background

Parents in this group have a similar problem; the difficulties they face managing their children's disability, and the stigmatisation and exclusion not only of the parents themselves, but of their children with intellectual disability and their families, as well as friends and workers of institutions that provides any kind of support to their children.

- **A Need for Inclusion**

While parents may join initially out of a strong need for support and understanding, over time, participants will form real bonds of friendship and partnership as they face their problems of exclusion and stigmatization together.

- **Independence**

Member organizations of Inclusion Ghana can facilitate and support the start-up of the PSHGs, however the end goal is for the independent functioning of these groups.

- **Co-operation and Mutual Support**

PSHGs are based on the principles of sharing and working co-operatively, as well as the mutual support cultivated between parents of children with intellectual disabilities.

2.2 The focus of the Parents Self-Help Groups

As far as persons with intellectual disabilities are concerned, Parent Self-Help Groups would be the joining of parents, guardians and/or caregivers to form groups. The focus of these parent self-help groups is to share experiences, build strong relationships and to build mutual support networks, creating a platform for advocacy work, development of skills required to raise a child with intellectual disability, and meeting other needs that parents of PWIDs may identify.

- Provide mutual support to parents of PWIDs through the sharing of experiences i.e. stories, stresses, feelings, issues, and successes
- Decrease isolation felt by parents of PWIDs
- Learn about the various services that are available to persons with intellectual disability
- Provide practical help to parents, for example, ways of coping with the feelings of exclusion and stigmatisation

3. Starting the Parent Self-Help Group

A lot of effort is required to set up a PSHG. This is primarily due to the fact that most parents with children with intellectual disability do not see the point in meeting with other parents of PWIDs. However hundreds of these groups are started each month by ordinary people with a little bit of courage, a fair sense of commitment, and a good amount of caring. As a member of Inclusion Ghana, you are already working with PWIDs, so identifying the parents is a step you've already taken. But what to do next?

3.1 Where to start – steps you can take

Inclusion Ghana's Members take the lead in facilitating this group and then pull out at some point. Member Organisations will need to speak to the parents that they already deliver services to. This can be a bit daunting at first; however, you may already have experience with this from your involvement in meetings and through your work delivering services to these parents. Think about what has helped you understand what is going on, what you have found useful, and how you know that decisions are being implemented.

Suggestions you may want to use with your group:

- **Involve others.** Two are stronger than one. Identify one parent who can support you with the group start-up, and who can share responsibilities and ideas.
- **Think about leadership (especially who will run the first meeting).** As stated earlier in these guidelines, members of the PSHG should be prepared to take on some responsibilities or to do something to help themselves. Brainstorm and discuss with other parents about who would be interested in assuming certain roles in the group. (Note that parents need to share responsibility and should not depend on one key member).
- **Objectives of the group you wish to form.** What is the purpose of the PSHG? Focus on building a safe environment where members can share experiences as a first step. You may want to set other objectives as well but focus on creating a platform to share. Don't be over-ambitious; parents have to start from somewhere! It is not how big the group grows, but how well it functions.
- **Membership group size can vary.** Do not be too anxious about obtaining a large number of parents. Inclusion Ghana suggests to form a group that has between five (5) to ten (10) members. It is more important to create a small core group of people who are committed to supporting each other than to have a large group that is less committed.

Bear in mind that this parents self-help group will sometimes share emotional experiences. Therefore, to encourage sharing, this group should all be parents of children with some type of intellectual disability. As the group members create a sense of belonging, it will become easier for them to share their experiences and challenges. The parents of the group share a common history of exclusion by society and the group should focus on their collective experiences and challenges, as well as their solutions and successes. The group should not focus on their children. Parents belonging to a group will also be empowered to break certain myths, views, and perceptions of society towards persons with intellectual disability. For instance, a common myth of society is that intellectual disabilities are a spiritual problem and can be cured, this belief is also held by some parents of PWIDs.

3.2 The agenda of the first meeting

Develop an agenda for the first meeting. Start informally and offer all parents a chance to get to know each other. The first meeting may be devoted to discussing the purpose of the group and/or organizational issues.

Suggested Issues for Discussion at the First Meeting:

1. Get to know each other

If the parents attending the first meeting are likely to be future members, take time for everyone to get to know each other. Find a name game or exercise that can be used to get to know everyone's name, location, name of their child, type of disability, etc.

2. What PSHGs are

Educate potential group members about how the PSHG functions and provides a mutual support network.

3. Purpose of the group

As a group, define in plain words what the group wants to achieve. Inclusion Ghana suggests that you start with a platform of sharing experiences to provide emotional support and practical help to parents of PWIDs.

4. The Need for a Parents Self-Help Group

At this stage you will have a detailed idea about what the parent self-help group should be about. Emphasize to potential group members that the joining together will give them the support they need to improve their situation. Let parents know that being part of a group will help them to understand their roles as parents of PWIDs and their children better through the sharing of experiences and challenges.

5. Frequency of meetings

Set out meeting periods, every month, every two months, or quarterly. Come to an agreed meeting frequency as a group.

6. Where to meet

As a group, decide where meetings will take place. Meetings may take place at a permanent venue, a new venue with every meeting, or at the residences of group members. Holding meeting in each member's house will foster inclusion and belonging within the group.

7. Roles in the group

Parents should understand that each member of the Parents Self Help Group is ready to take responsibility and action to improve their situation. They should know that the Group functions based on a mutual support network. Therefore, the different roles in the group can be shared amongst its members. Leadership roles should be filled by the parents because this is their platform. The roles therefore in the Group can be shared among parents. Again the emphasis here is on parents taking major or lead roles because it is their platform.

8. Membership

Membership should be restricted to parents and/or caregivers of PWIDs only.

9. Set ground rules

To create a safe and inviting environment for sharing, it is important to set common ground rules. Ask parents what they feel is important for the group. Examples of rules may include that phones are switched off or put on silent, or that members do not bring their children.

It is helpful to prepare an attendance list with people's names and addresses so that you can write to and thank all attendants, as well as follow-up later to find out interest levels in joining the group.

3.3 Planning the first meeting

When planning the first meeting, you will need to consider accessibility of the meeting place, especially if people with disabilities are involved. Pick a convenient location that is easy to find and that can comfortably hold the maximum number of people you expect to attend. This does not have to be a permanent meeting place. Make sure that this place is accessible to everybody you target. This can be

your office, a church or mosque, or a community centre.

Do you want to open the meeting to the public by advertising? You may wish to post notices in places like special schools, doctors' offices, community centres, or other locations where your prospective members might see them.

You will also need to consider the time; be on the lookout for other events/activities that are likely to affect attendance and try to have the first meeting afterwards. For example, do not organise the first meeting on a Friday when people may attend funerals, or during rainy seasons.

3.3.1 The First Meeting: Things to remember

- Have an attendance list for parents' to sign as they arrive. It is always helpful to have a mailing list of potential members. Even if all participants were invited, you may want to get phone numbers or other information. You might want to add one or two identifiers to this list, such as the age of their child, the school their child attends, or whatever information you think may be useful in selecting future activities and that will enable you to follow-up. Be sure guests understand that they are not signing up to be members or volunteering to do anything; this is an informational list only.
- Remind parents of the meeting time and place
- Get there early and make sure everything is set up as you want it. Make sure there are seats for everybody.
- Make sure people know how to find the meeting place. You may need to put signs at the door directing people to the meeting room, or station people around the meeting room to direct others.

Suggestions for the meeting

- Go through the items on your agenda. Don't rush, but keep the meeting moving.
- If possible, elect an interim leaders of the group
- Set a time and place for the next meeting, you can rotate the meetings to take place in the houses of the group members who agree to host meetings.
- Identify possible topics for discussion at future meetings.
- Allow time for socializing and discussion. It's important for parents to be able to talk to one another; it's also important not to let this aspect "take over" the meeting.
- End on time.

3.4 Follow up after the first meeting

The interim leaders appointed during the first meeting should write brief reports from the meeting. The interim leaders should also thank the attendees for coming to the meeting, without mentioning their names. In this message, you may wish to:

- Give some statistics on the people who attended the first meeting. For example, you might be able to say that 80% of those who attended were parents; over half of their children are under

age 8, and/or that most of the children are identified as having intellectual disability.

- Reiterate any decisions that were reached at the meeting, including the name of the group, its officers, the time and place of the next meeting, and reminders of actions to be taken if there are any
- Describe any nominations or elections that have been planned.
- Make requests for any help needed. Be specific about what is required and the time commitment of the task
- Provide a means for those who attended to make suggestions and recommend future agenda items.
- Let parents know how to get in touch with you and other leaders.

4 Future Meetings and Activities

Maintain a list of agreed upon activities to ensure the solidarity of the group. Ask from time to time if parents want to change their meeting place or time, about any issues of concern to parents, and ideas for future speakers or topics of discussion. Encourage parents to share their opinions and ideas, and to ask for information when they are unsure about the issue that is being discussed. Remember to debate the issues, not the persons who present them. Suggestions for the agenda of future meetings can be found in appendix 1.

As your group becomes more established, there may be other questions to consider. Many possible questions are listed below. Although not all will be relevant to your group, this list may help the group decide upon future activities or directions.

- What are your group's long-term goals?
- What do your members want to learn more about?
- Do you want to offer or participate in training programs?
- Who will arrange for speakers or topics for the meetings?
- Who will contact members and advertise the meetings?
- Do you want people to be able to reach your group by phone? Whose number will they call?
- Will you provide refreshments at the meetings? How will you pay for this?
- What if only a few close people show up for the meeting?

Campaigning

You and your group will know first-hand what it is like to live with your problem, and what helps you cope with it. If you feel you want to tell people who plan and provide services how you feel about them, then go ahead and do so. This does not necessarily mean that you need to wave banners and placards. The method of campaigning will have to depend on you, and your relationships with professionals and policy holders. They may sometimes approach you.

Social Activities

Do not feel that you have to have these as a matter of course. Sometimes social activities are best when impulsive, informal and outside the normal pattern of meetings. But some organised events may contribute to maintaining the momentum of a parents' self-help group. Keep it simple and cheap to start with and have something that doesn't depend on large numbers of participants. Some suggested social events include: a game of football between 2 PSHGs, a movie or documentary, a gathering with the children, going to the market or church, parents helping one another to take care of their children with intellectual disability, and/or parents having each other over for dinner or lunch. Remember not to engage in activities that may demand a lot of funding.

4.1 Independence of the Group

The ultimate goal is that the group is run by parents and is a forum for the parents. If you as a facilitator are not a parent you may need to pull out at a certain point.

5 Keep the group alive

You will find that the group membership will always change. Some parents may leave the group or become dormant members whereas others may want to join.

Hopefully new members might have been waiting to join the group. New members can be attracted by word-of-mouth publicity and by sharing or providing information about the groups in the member organisations. In case new members join the group should not forget to give them time to introduce themselves and to get to know the existing members of the group. It will be worthwhile to appoint an existing member of the group to tell the new member more about the group's history and share information on what topics have been discussed before. You can choose to pair an old member with the new member for contact and welcoming.

5.1 New members

The number of members allowed to join the group at any given time should be agreed upon. This will keep the group size small and manageable, and allow for interaction between members. In case more parents want to join a group that has reached its maximum membership limit, a new group can be created for these interested individuals. You may want to consider the following:

- Encourage members to do word-of-mouth publicity.
- Continue to send meeting announcements on a regular basis to Inclusion Ghana to post on the website and in newsletters, in special schools, churches, and/or community centres.
- It is possible to split your group if it grows beyond the maximum number or if you feel it is getting too big

5.2 Keeping up Interest

A group is made up of parents who may have distinct ideas of what's interesting, required, or convenient. Be sure to keep communications open, and try to elicit ideas and participation from all parents. A group managed entirely by a few members runs the risk of not only overworking their leaders, but also of having no pool of upcoming leaders to carry on the work. Next year's success, or even the continuation of your group, will depend upon identifying new leaders and volunteers and upon maintaining a sense of interest and commitment.

To keep your leaders from burning out, and to provide opportunities for new leadership, you may want to:

- Share and delegate the tasks to be performed
- Have as many parents actively involved as possible
- Have one-time-only activities that parents can choose from
- Evaluate your meetings on a regular basis. Discuss what you've been doing, how it meets your purposes, which topics were interesting, which were less interesting. This evaluation can be used to learn from past experiences and improve upon your meetings in the future.
- Make your program as varied as possible.

Many people cannot commit themselves to an activity, but will certainly help out for an hour or two. It is also useful to discuss your mission every year, and redirect it, if necessary. Schools change, communities change, your membership may change, and children are always changing. What is important one year may not be a burning issue next year. Examining the mission of your group can play a critical role in evaluating your successes, learning from your mistakes and experiences, identifying new goals and needs, redirecting your efforts, and maintaining and renewing members' interest in the group.

6 Potential challenges within the Group

Nobody joins a group to create problems, but especially in groups that run a bit longer you may want to prepare for some challenges. Below is a list of some common problems that your parent self-help group may experience as its membership grows:

a) Meetings turning into complaint sessions

Parents "dump" their problems on the group and other group members don't offer solutions or support; they just offer more complaints. There is no balance of people talking about their problems and others relating their own experiences in dealing with similar problems or offering solutions.

Possible Solutions:

- Don't move on to another person's problem until the first one has been addressed. Invite others to share possible solutions after the person finishes sharing his/her experience.
- Make it a ground rule that each member must state something positive that happened to

them since the last meeting.

- Ask parents to come up with possible ways to deal with the problems presented during meetings, and to talk about their ideas at the next group meeting. Make sure that the agenda sets aside time for members to discuss what they've thought about or learned in between meetings. Ask parents which of these ideas they plan to use. This puts the emphasis on making progress and taking action.
- The facilitator can state his or her reaction to the way the meeting is going without blaming or criticizing. The facilitator's way of reacting can provide a model for members
- Remind the group they all have the responsibility for how a meeting is going.

b) Parents may be passive

Members feel reluctant to talk or don't talk, they don't take on an active role, and don't talk about themselves or their problems.

Possible Solutions:

- Remember, silence is not necessarily a deficit. New members may not feel comfortable expressing their feelings or ideas in front of people whom they have just met, and may need a few meetings before they feel free to talk.
- Continue to be encouraging. It takes some people a while before you can build up that person's confidence. Thank them for attending, directly offer them a chance to speak at the meeting, and let them know that any contribution they make is important and valuable. Sometimes patience is necessary to allow the person to grow.
- Set an example: be the first person to talk and share. If people hear others talking and sharing, they will be more inclined to do it themselves.
- Try using a neutral activity, such as bringing in an article and discussing it. Sometimes people will feel more comfortable talking about specific issues instead of themselves. Once they get used to talking in the group, they may feel more comfortable talking about themselves.
- Use questions to invite members into the conversation. Perhaps a member would like to talk, but they are a little shy, they feel that other people's problems are more pressing or valuable, or just need a little nudge.
- Remind the group that different ideas and opinions exist. What works in one situation may not work in another, and every human being is different. One of the strengths of a support group is to expose people to different options.

c) Some parents may dominate the discussion

Monopolizers may take up too much of the time allotted to the group discussion. Other persons who would like to contribute cannot break into the conversation. Other members of the group may be bored.

Possible Solutions

- Tell the parent you appreciate their input/contribution to the group, but others need to be heard from too. You don't want to quiet someone completely because everyone has something valuable to share. Let them know that their opinion is valued, but point out that the opinion of others is also important. Most people who monopolize the conversation don't realize what they are doing.
- Set a time limit. You can have a time limit set in place for everyone and be able to prompt any member who is violating it. Your group could also agree to use some kind of unspoken signal/ non verbal communication to quietly let someone know that it's time to hear from someone else.

d) The Group may fall off topic

The group ends up talking about other things besides the meeting topic. This may not be a problem but you need to check.

Possible Solutions

- Remind the group of the agenda, and push the conversation back to it. This is why you have an agenda, and why it should be agreed upon.
- Ask the group if people are having a lot of strong feelings about the topic. If everybody agrees that the topic of the agenda is being changed, then there is no problem.

e) Confidentiality may be violated

Parents are quiet and are not sharing their personal experiences and feelings. If group members have been very actively sharing information but suddenly stop, you may suspect that confidentiality has been breached.

Possible solutions

- Have a ground rule about confidentiality. If you only have one rule, make it this rule
- Remind parents what confidentiality means; some people might just not understand. In the simplest terms it means, "What is said in this room stays in this room." It also means that people shouldn't be talking about what happened at the meeting with group members unless they keep the conversation strictly about themselves.
- Re-emphasize the critical importance of keeping what is said in the meeting "in the room." People must feel safe about sharing in a group. If they think that there is even a small chance that what they say will "get around," then no one will share much.

Tips for facilitation in general

- Have ground rules that spell out what is acceptable and unacceptable group behaviour and reflect on the ground rules every now and then

- Make sure that the meeting place is safe (both physically and emotionally)
- Begin the meetings by inquiring if there are any issues that members would like to talk about
- Listen and ask questions—don't assume that you fully understand
- Question, clarify and use constructive feedback

Also confront disruptive members at it serves as:

- Matter of courtesy
- Respect for all group members
- Excellent modelling opportunity
- Crucial to group morale and purpose

7 The role of Inclusion Ghana in Parent Self-Help Groups

Inclusion Ghana's mission is to work to reduce stigmatization and ensure full inclusion of all persons with intellectual disabilities (PWIDs) and their families by advocating for their rights and needs. Inclusion Ghana strongly believes in the added value of Parent Self Help Groups. We support our member organisations as much as possible in the process of forming the groups and maintaining them. The member organisations of Inclusion Ghana are in direct contact with the parents and are the key players in initiating the groups. We believe that the sharing of experiences and knowledge between people who live in similar circumstances is key, as challenges one parent faces, may already have been overcome by another parent. To support Member Organisations, Inclusion Ghana will:

- provide members and group leaders with training on how to lead a group and facilitate a meeting.
- give advice and suggestions on specialists to involve in your group meetings;
- give you ideas on participatory exercises and energizers that you can use during your meetings;
- link you to other support groups that are at a similar stage as your group, groups that have really worked well or groups that have been through similar challenges that your group is currently facing;
- identify and link groups to opportunities that may benefit them

To support the PSHGs, we expect the member organisation to:

- Facilitate the start up process of new groups
- Aim for all parents in their network to be part of a PSHG
- Share experiences about the groups and the process of forming them in network meetings for member organisations that Inclusion Ghana will organise;
- Refer to Inclusion Ghana when you face any challenge.

To measure the level of impact we expect our member organisation to:

- Give us a quarterly update on the number of PSHGs that are running and the number of meetings they have had;

Appendix 1

Suggested agenda for meetings

The following may be helpful in setting up a meeting structure for your parent group. These activities are common to some self-help group meetings and can be used as an initial guide for structuring your meetings. It is not necessary to incorporate every activity mentioned here in each meeting agenda.

- Welcoming New parents:

Spend some time making the new parents feel comfortable

- Formal Opening of Meeting

- Introduction of all parents:

Going around the room, each parent can introduce himself/herself or briefly share their most impressive experience since the last meeting.

- Sharing Experiences:

Most of the meeting time should be allocated to the sharing of personal experiences and helping each other. You could ask one parent to prepare a story based on a recent experience to open the floor for others to share.

- Discussion, Education, and Information Sharing:

It can be helpful to regularly ask members to suggest topics that are of interest to them. Groups can also invite guest speakers to address issues. Suggestions for topics to discuss are:

- ◆ Different forms of intellectual disabilities
- ◆ Special education
- ◆ Speech therapy
- ◆ Ways to involve your child in house work/community work/living independently
- ◆ Games to play with your child

- Business/Planning Section:

This time can be set aside for any business the group wishes to do, such as planning projects, arranging future meetings (choosing topics, speakers, etc.), making announcements.

- Reflection:

It is important that the group evaluates the meeting. What went well, what should be done differently. By listening to members' feedback, future meetings can be more focused on parents' needs to make it more effective and efficient.

- Formal Closing:

Give some signal to indicate that the meeting is formally closed, e.g., a closing prayer at the end of each meeting. Parents should be reminded of time and place of the next meeting.

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