

Additional Module

BUILDING FOUNDATIONS



This module is a little different from the other sessions in that ideally any follow up needs to run in parallel to the other modules. This important issue requires thinking about from the PLANNING PHASE of the programme (see Module 0 Before you Begin).

When is the right time to run this module? There is no 'right or wrong' time. If you are working in a very poor area, then you may need to prioritise this module earlier, and it will also be a useful incentive for attendance. We know that it is important to allow for some time to build up trust amongst the group members. We recommend that it is Session 5 or 6.

A livelihoods approach should NOT add to the burden of caregiving but instead facilitate caregiver empowerment.

FACILITATOR TIP

- This module is about 'livelihoods' - about **how individuals or households are able to meet their basic needs**. This can include initiatives to support access to formal or informal employment, forming and/or participating in savings groups, **knowing what rights you have** (e.g. to poverty alleviation programmes, disability benefits, better quality public housing etc.), and how best to access them.
- We know that many caregivers struggle to return to working after having a child with a disability. We also know caregiving can be costly, and that poverty can spiral when unsupported. [1, 2].
- READ all of the **CASE studies for Activity 2** before you run this session.. Don't focus on one solution- ONE SIZE DOES NOT FIT ALL. This activity can take extra time. If time is limiting then make a selection of case studies or share between members.
- Link to the '*Our Community Module*' where we identified local organisations. This might be local NGOs and/or local/regional government who have programmes to support livelihoods. You need to understand how the group members can access these programmes and to work in partnership with local organisations to deliver on this module and follow up. For example, a member of the local government who can explain and support applications for local poverty alleviation initiatives.
- It is important that you MANAGE the expectations of the group. Explain from the outset that this session is about sharing ideas for solutions.



MATERIALS copies of case studies



ICEBREAKER:

We all have lots of valuable skills and experience

Ask everyone to stand/sit in a circle, and chat to their neighbour for 5 minutes about what kind of 'work' they did before having their child(ren)? By work, this can mean working in the home or in the fields, or going out to work e.g. to the market, as a hairdresser, tailor etc. or paid employment.

Ask each participant to introduce their other pair by saying two things about them:

1) a skill that they have for acquired through working and 2) a POSITIVE personal QUALITY which you feel they bring to the group

Give a couple of examples and make them fun and always positive!

- Maria is good at sewing, and she is a very good listener.
- Rachel knows how to grow vegetables and is always very patient.
- Eva is a nurse, and always makes me laugh in the group.



Key points to summarise:

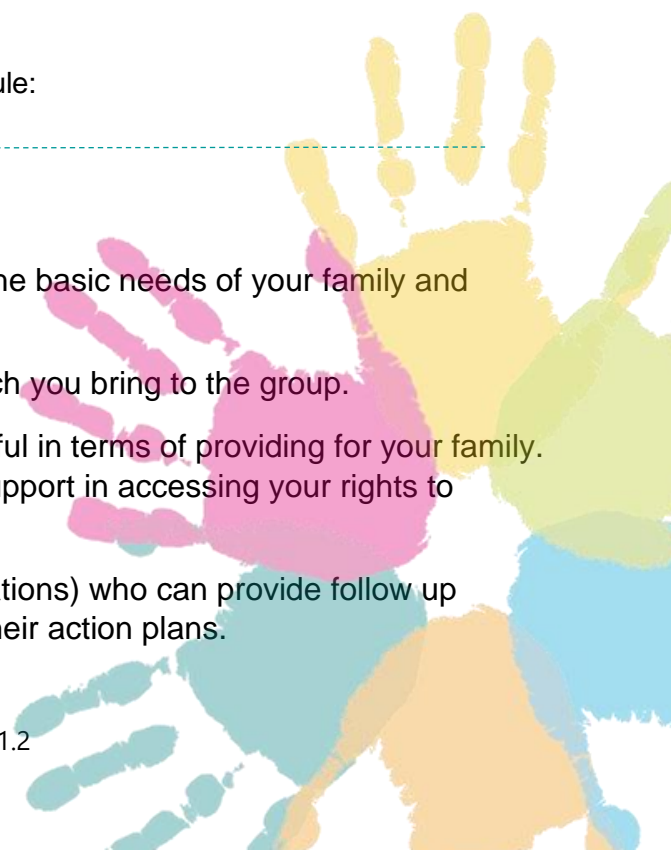
- We all have lots of valuable experience and important life skills which we can use and share with each other.
- In this session we will be looking at how to BEGIN to address some of the challenges around meeting the basic needs of our family.



EXPLAIN Outcomes for the module:

As a caregiver you will:

- Share challenges that you face in providing for the basic needs of your family and discussed their ideas to address them.
- Discuss your work experience and life skills which you bring to the group.
- Identify the skills and knowledge that will be useful in terms of providing for your family. E.g. new business or technical skills needed, support in accessing your rights to services,
- Identify allies or partners (individuals or organisations) who can provide follow up support to you and the group in taking forward their action plans.





ACTIVITY 1:

What are some of the challenges that you face in meeting the basic needs of your family?

In groups of 3- 4 discuss the following questions:

- Are there any worries that you have in meeting the needs of your family? This may be financial worries but can include other issues, such as having enough food.
- Have you been able to return to any work (any type of working or generating income)? What has helped/not helped?
- Have you been able to access any government social support programmes e.g. disability benefits, poverty alleviation programmes.

TAKE NOTES of key issues, on a flipchart. Explain we will be coming back to these issues.

The key issues are likely to be:

A variety of financial worries, including the additional costs of caregiving.

May not have been able to return to work. Ensure that the issue of childcare comes up as this is an important consideration

“In most families I have worked with, especially in the villages, the husband was the main breadwinner. After having a child with a disability, the husband frequently left, and the mother really struggled to generate money” - CBR Manager, Uganda



ACTIVITY 2:

Learning lessons from other caregiver groups

Explain that we will be looking at some example from around the world on how other caregiver groups have started to address these challenges. Work in groups of 2-3. Ask one person to read the case study and then discuss.

As a facilitator make sure you have read ALL the case studies in advance.

Allow for about 1 hour. Share out the case studies. Each group should have 2-3 case studies.

- For each case study, discuss the key points and questions.
- Each group then provides feedback on their case studies.

Summarise the key issues:

- We are NOT saying that one approach is better than another. In the different examples, individuals and groups had different ideas about how to support their family.
- We all have valuable skills and experience which we can use.
- Childcare is an important issue that needs to be considered.
- Build on your existing skills and experience in the group and learn from each other.
- A common challenge raised is getting 'seed money' (some initial capital) to set up the business. These case studies show that there are different ways to address this.
- There can be both BENEFITS and CHALLENGES to setting up a new business.
- If a group starts to run a Savings Programme, and manages money, then in many countries you may need to officially register the group with a government department. You may also need to set up a bank account. It may be easier to join existing Savings Groups in the village rather than setting up their own. There is NOT time to cover this in detail in the session, but it is a key issue that has to be considered. It is essential to partner with another organisation that has expertise in this.





ACTIVITY 3:

Your ideas for your community

FACILITATOR TIPS

- This activity is intended to be a first step only in planning ideas
- Encourage the group to think about which local organisations or people (allies or champions) who can help them in planning their next steps.
- Childcare and 'Respite' (*allowing the caregiver to have some rest from caregiving*) can be really crucial for many caregivers. Look at ways they may help each other, or find help within the family. It is also important to think about how they can demand their right for childcare e.g. can they get their child into a day care centre (if they exist in that context).
- CHECK the 'Our Community' module, and review how to access Disability Benefits or Poverty Alleviation Programmes that are available. Many caregivers are eligible for these, but we know that they struggle to access them. Ask them to share if they have been successful with these grants. You will also need to be familiar with the grant system.
- It is essential that other organisations are invited to help with this session and/or follow up. For example, invite an OPD (Organisation of Persons with a Disability) to input. Think about which organisations might help with some skills training..

We have heard from other caregiver experiences and now it is useful to think about what could work for you in your community. Briefly remind them of the main challenges identified in Activity 1, and ask them to BRAINSTORM ideas they have to address their challenges. Allow 1 hour.

One member per group completes the table on the flipchart (see table below) or the facilitator can complete the table as each group provides feedback.

Prompt questions:

- What ideas do you have?
- How can you manage childcare - what are the different options?
- Have any of you had previous experience in other groups (e.g. village savings, or running businesses) that you can share?
- Do you know anybody, or any organisation that could help.
- How can you help each other?

Finish the session by summarising the main ideas. Ask participants to agree on NEXT STEPS and FOLLOW up required

The following table gives examples of key challenges identified from Activity 1 and how to address them.

Challenge identified (Activity 1)	Ideas	Next steps
Unable to return to work	<p>Ideas for new skills training, e.g.</p> <p>Business skills</p> <p>Basic financial skills such as book-keeping</p> <p>Ideas for a new income generating activity</p>	<p>MAKE a list of important people in your community and think about how they can help the group.</p> <p>Think about who is most likely to give up their time and support the group - which contacts do you have?</p> <p>Ask caregivers who have returned to work how they are making a success of it</p>
No one will look after my child	Help each other with child care	<p>Find out what other local childcare options exist.</p> <p>Plan how they might be able to help each other with childcare</p>
Poverty- No seed money for a new business	Savings groups- either joining one in the community or starting your own	<p>What else might you need to do?</p> <p>Who could help you set this up?</p> <p>What steps which would need to be taken</p>
Other		

TAKE HOME MESSAGES

- We have the right to access disability benefits and other poverty alleviation programmes
- Everyone has valuable skills and experience to share in the group which will help each other. Together we are stronger.
- It is good to work with 'others' (*working in partnership*) to help us gain new skills and training, or to provide valuable ongoing support in a new business.
- We may need to *adapt* how we work so it can fit with childcare.
- We may need to think about different options for childcare. This includes ensuring that children with disabilities are supported by other family members, and welcome in childcare facilities
- One size does not fit all. We need to find what works in our community setting.

Acknowledgements

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References

The module content has informed by; a scoping review and global survey and interviews with a variety of key stakeholders.

A selection of references include:

1. *Kyeremateng, J.D.A., et al., Experiences of primary caregivers of children with cerebral palsy across the trajectory of diagnoses in Ghana. African Journal of Disability, 2019. 8: p. 577.*
2. *Mkabile, S., et al., African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies. African Journal of Disability, 2021. 10.*
3. *Zuurmond, M., et al., Illuminating the empowerment journey of caregivers of children with disabilities: understanding lessons learnt from Ghana. Africa Journal of Disability (accepted for publication-forthcoming), 2020.*
4. *Sandy, P.T., J.C. Kgole, and T.R. Mavundla, Support needs of caregivers: case studies in South Africa. Int Nurs Rev, 2013. 60(3): p. 344-50.*

Materials for Activity 2: Livelihood Case studies

As a facilitator make sure you have read ALL the case studies in advance.

Case Study 1: Special Mothers Project Ghana

This is a group of mothers who have children with developmental disabilities in Ghana. Several mothers came forward with ideas for setting up a business.

One woman was a hairdresser and struggled to return to work. The group helped her with some small capital to start selling wigs. She has expanded this business to setting ladies handbags and shoes.

Another mother was a seamstress, but she found it difficult to work because of caring for her child. The group members helped her raise some money in the community, so she started to sell sewing equipment instead from her house, with materials like thread, and needles.

A third mother needed to be able to be close to her home so that she could care for her daughter. She was supported by the group to buy a popcorn machine and sells at the roadside next to her house. The group helped her to access funding for small businesses through a local government scheme.



Figure 1: picture of popcorn machine

Key points in Case Study 1:

- ✓ The women already have valuable skills and experience.
- ✓ In many cases it is helping them to think about how they can return to work OR **how they can adapt their work** so that it can fit around childcare.
- ✓ There were **different sources of funding** to help with the 'seed money' from: public sources (crowdfunding), from local government opportunities, and help from within the group.

Further prompt questions:

- Where can different sources of funding come from in your local context?
- Are there organisations who might be interested in supporting the group e.g. The local church/faith-based organisation, government funding? How can you find out more about possible sources of funding for businesses, and who could help you with this?

Case Study 2 : Working in Partnership with Street Business School - Uganda

Street Business school is a small NGO that offers business and entrepreneurship training to women.

Jackie and Maureen (both mothers of children with disabilities) received training on business skills. They now run training for other caregivers and family members on: business planning, book-keeping, money management, finding capital, and confidence building. Jackie and Maureen stay in touch with the Street Business School for ongoing help.

Mama Mark here smiling in the picture has set up a small shop (pictured) following training.

"Previously I had feared to start my own business, but the training gave me confidence. We studied record keeping and ways to increase your customers.

See www.streetbusinessschool.org for more information on their work



Figure 2 Woman in Uganda selling from her small shop

Key points in Case Study 2:

- ✓ This is about **working in partnership** with another local organisation (Street Business School) which has expertise in setting up small enterprises.
- ✓ They offered skills training for the mothers.
- ✓ They also offered 'mentoring' so that the mothers were better supported over a longer period. This recognises that setting up a business is not easy, and many will require ongoing support.

Further prompt questions:

- Discuss in your group if you know of other organisations local to you who could provide such training and support?
- Plan to invite these organisations to come and talk to your , or plan to send a couple of your members to talk to them about how you can be included in their work.

Case Study 3: Special Mothers project and Government support

The Special Mothers Project is a small support organisation of mothers in Ghana. They collaborated with other disability organizations and went to the National Council of Persons with Disability. They argued that parents of children with disability also need to receive disability benefits.

A few families have now benefited from monies ranging from a \$ 150- \$800. This seed money was used for the purchase of a sewing machine for one caregiver and a freezer from another.

The mothers also met with the Ministry of Information to also discuss the need for suitable childcare and access to school, which will enable mothers to return to work. They also discussed how the National Health Insurance scheme should cover medication needed for their children

Ministry of Information Pledges support to the Special Mothers Project



Figure 3 Members of the Special Mothers Project meeting Ministry staff

Key points in Case Study 3:

- ✓ The group worked together with other disability organisations, and Women's organisations, to demand their rights. They used the fund as seed money for some of the women to start a business.
- ✓ The mothers also 'lobbied for' (argued their case) to expand the Health Insurance Programme so that it also covers some of the costs of looking after a child with disability.
- ✓ Some working mothers also argued for more help with childcare to enable them to return to work.

Further prompt questions:

- Do you know which benefits that you have a right to in your country?
- Are there any Women's Programmes that you can access?
- Are there other rights which you want to fight for in your community?

Case Study 4 : Carer's Worldwide

Carers group, India

Kalibati cares full time for her grandson who has multiple disabilities, and this leaves her no time to work, socialise, or look after her own health. She joined a carer's group, and through funding from the project she was able to set up a grocery in her home which also allowed her to care for her grandson.



Figure 5 Grandmother supporting her grandson, Nepal

Jyoti's Carers group, Nepal

The Jyoti's carer group save \$5 per month which is held in a joint account. This growing pot of money is available to group members to provide emergency loans to meet unexpected medical or household costs. Some carers have also taken part in basic training on how to make shoes. They have begun making shoes and are generating a steady income. They plan to undergo more advanced training soon

For more information see carers worldwide at <https://carersworldwide.org>

Key points in Case Study 4:

- ✓ The grandmother in India adapted to her situation by setting up the project at her home.
- ✓ The group in Nepal benefited from some skills training from a Partner organisation. This organisation helped them to develop a 'business plan' to check the feasibility for setting up a new business. This helps to weigh up the risks and benefits.
- ✓ A small amount of savings can help with emergencies for some families.

Further prompt questions:

- How might you need to adapt your work if you also have a caring role
- Are there other people or organisations that could provide you with some training?
- Do you have any experience in a savings group in your community? Is there any advice you have for the group?

Case study 5 : SEEK project Kenya

Project **SEEK** in Kenya works with self-help groups of caregivers (mainly mums) with children with disabilities.

Some of the members contribute either a **small sum of money** or **food stuffs** (e.g. bag of wheat flour, sugar) at each meeting (called a 'merry-go around activity').

The group treasurer collects the contributions, and the secretary records it in the group's book. The full amount is given to nominated members. The food stuffs are shared, and also sold at a local market.

Some groups carry out 'table-banking'. A fixed amount of money is agreed for members to bring to each meeting. Members make bids for the amount they wish to borrow as capital for their own livelihood project and will pay back their loans with small interest. The group needed to be register and set up a bank account. This only works well when there is a high level of trust in the group,

One example of an unsuccessful project was rearing chickens. Infections and bird flu threatened the survival of these flocks. One group lacked the money to pay for important medication, which led to the whole flock dying.

Key points in Case Study 5:

- ✓ Some groups were successful with their project, but others were not. It is important to weigh up the RISKS of any new project, as well as the BENEFITS.
- ✓ Find people who have knowledge and expertise to help out.
- ✓ If you start to collect money in the group, then in some countries you have to 'register' the group officially with the local government. You may need to set up a bank account. It is strongly advised that any group has additional help and guidance on this.

Further prompt questions:

- Do any of the group members have experience of being involved in similar activities? How did it work? What were some of the advantages, and challenges?
- Are there other people or organisations that could help your group

Case Study 6: PIH Programme Rwanda

Partners in Health in Rwanda support several caregiver groups in a rural area. The ICYZERE (meaning 'hope') group is in the eastern province of Rwanda and is made of 22 caregivers with children with developmental disabilities. After completing the Ubuntu programme, the group continued to meet monthly and save 500 Rwanda Francs (\$0.5) per month. After several months of saving, the mothers rented a small lot of land to farm collectively different crops for every group member to get basic needs for their daily living.

The group has also received technical support from another project and were provided seeds for maize farming and a kitchen garden.

The Tubakunde group is another caregivers group of 9 mothers in the eastern province of Rwanda.. They started a small savings programme and give small loans between themselves. Afterwards they started to make hand crafts. The district hospital social worker provided them basic training on making different handcrafts. The group were able to get some materials from their savings. The group's ambition is to make more clothes and seek further trainings in handcrafting.

The above two groups have a good structure of organization comprised of 1) a president of the group, 2) secretary, and 3) treasurer to coordinate and monitor all groups activities.



Key points for Case Study 6 :

- ✓ The mothers came up with their own ideas, and this varied from place to place.
- ✓ The group received technical support from other key people.

Further prompt questions:

- Do any of the group members have experience of being involved in similar activities? How did it work?
- Do you think there are differences in what can work in a village, compared to a city? Why? How does that relate to your setting?

Case Study 7 : Parenting Programme in Peru

Training on business skills was provided to a parent programme in Peru. One family decided to set up a small bakery business. The mother already had bakery skills, but needed help in how to set up a new business. The family was helped to apply for government funding to start the project.

Over time, the family also benefited from ongoing support from a local government training programme for small businesses, and they developed a network amongst local business leaders which helped them more over time.

Key points in Case Study 7:

- ✓ The mother already had valuable skills and was helped to use them.
- ✓ The family was supported to link in with local government initiatives.
- ✓ A new business is likely to need ongoing support. It is important to find ways that you might be able to benefit from other support from the government or private businesses.

Further prompt questions:

- Do you know of government training that might be available? How can you find out if there is?
- Do you think it is important to use the skills that you already have? Why do you think the project in Peru was so successful?

