

# Caring for People with Physical Disabilities



## Best Practice in Person-centred Care

**Authors:** Michael Miro; Abdikadir Ismail; Ahmed Nabeel Alvi; Billie Bbosa; Angela Foley; Maeve Moynihan; Thandiwe Gwarumba; Maytham Al Zubaidi

**Editors:** Jon Anderson; Maeve Moynihan; Nicolien Wassenaar



## Table of Contents

What inspired this manual?.....3	3.4. Physical exercise .....18
Exercises for learning Skills.....3	3.5. Devices that help..... 18
<b>SECTION ONE:</b>	3.6. Good record-keeping..... 20
<b>WHAT A CARER NEEDS TO LEARN.....4</b>	<b>SECTION FOUR:</b>
1.1. Introducing “Person-centred Care”.....4	<b>MAKING AND IMPLEMENTING</b>
1.2. Understanding individuals as part of groups. .5	<b>A CARE PLAN..... 21</b>
1.3. Understanding individuals as part of families.5	4.1. Coping with a diagnosis..... 21
1.4. Understanding individuals as part of Communities..... 6	4.2. Setting reasonable expectations .....21
1.5. Ensuring your clients’ Human Rights .....7	4.3. Setting goals for the Care Plan.....22
1.6. Going further with Person-centred Care.....8	4.4. Agreeing responsibilities.....23
<b>SECTION TWO:</b>	4.5. Awareness of barriers to using services.....23
<b>LEARNING MORE..... 9</b>	4.6. Monitoring & Evaluating .....24
2.1. Training and educating yourself .....9	4.7. Saying goodbye.....25
2.2. Finding 'helpful friends' for further learning and training..... 10	<b>SECTION FIVE:</b>
2.3. Support group learning activities.....10	<b>BACKGROUND NOTES.....26</b>
2.4. Viewing from a client’s perspective.....11	5.1. The politics of disability.....26
2.5. Supervision..... 14	5.2. Genetic causes of disability.....26
2.6. Caring For the Carers.....14	5.3. Carers and Gender..... 27
2.7. Family Carers..... 14	5.4. Institutions that can help or harm.....27
<b>SECTION THREE:</b>	<b>SECTION SIX:</b>
<b>THE WORK OF A CARER ..... 16</b>	<b>RESOURCES AND REFERENCES.....28</b>
3.1. What people need – and whether services are available..... 16	6.1. Hesperian Health Guides..... 28
3.2. The need for employment and income.....17	6.2. Networklearning manuals.....28
3.3. The need for mobility ..... 17	6.3. Further reading on issues raised..... 28
	6.4. DISABILITY ROLE-PLAYS.....29
	6.5. CHECK-LIST FOR INTERVIEWING SKILLS....31

## Caring for People with Physical Disabilities

### What inspired this manual?

Suggestions for this manual came both from carers as well as people who sometimes need caring themselves. What both groups said, above all, was this: too many people who need care find themselves being treated as if they were small children, or stupid, or just “a lump of flesh”. What they want is to be treated as **real human beings**, with their own individuality and desires.

People who need care want to be the centre of their own lives. They say that many carers could do better. And the supervisors of carers say the same thing. If you are a carer, this manual suggests ways of looking at your work to see if you are doing it well and in what ways it could be improved.

### Exercises for learning Skills

Learning new knowledge, attitudes and activities is important. But to transform these into new skills involves practice.

Most of a carer’s work involves three different skills:

- Physical skills
- Decision-making skills
- Communication and empathy skills

The **exercises** in this manual will guide you in developing these skills. You may have to carry them out more than once to feel you are competent.

**Checklists** will make sure you are working to a high enough standard.

You can follow the manual by yourself or, better, with a small **support group** of colleagues (see Section 2).

You can learn the physical skills – such as measuring a dose of cough syrup – to some extent on your own. But how will you motivate the one with the cough to take something that tastes nasty – and will you be able to discuss it in a way that they will see the value for themselves?

You will learn such decision-making and communication skills better if other people can give you feedback and enthusiasm. They can give you insight into what would work – or not – in real life and whether your standards are high enough.

## Section One: What a Carer needs to learn

### 1.1. Introducing “Person-centred Care”

With disability, resources for providing good care have for a long time been insufficient. Traditionally care programs have been set up by a) looking at groups of people in need, b) estimating the characteristics of each group, noting what others are doing (in the South, mostly through institutions), and then c) doing the same.

But today (2013), thinking has advanced. Clients have become more vocal and organised. And carers have observed, discussed, thought about and learned how to do their work in a more professional way. They have adopted a different mind set: putting the client at the centre of his or her own life. They call this 'Person-centred Care'. What does this mean?

**Person-centred care =  
The client is central; (s)he is offered quality care, with respect;  
the care is adapted according to the wishes (s)he expresses.**

This involves four things:

1. The client is central.
2. The care offered is as good as the circumstances allow.
3. The client is involved in decisions and has a deciding vote.
4. Each client should have their own Person-centred Care Plan.

#### **EXERCISE: HOW DO YOUR CLIENTS FIT INTO THIS DESIRED PERSON-CENTRED CARE?**

Make up a spreadsheet as below. In the first column (“Name”), list all the people with disabilities for whom you provide care. Add the names of family members who are disabled and other disabled people known to you. You are going to examine their situation and your own current attitudes.

Name	Age	Disability	Cause	Age when disabled	Living situation	Able to...	Not able to...	Unique because...

**Exercise Part One:** From your list of people with a disability, pick out two. Start thinking about them and enter your conclusions in the columns.

Bear in mind that everyone is as different and as complicated as you are. The more you can identify these differences the more information you will have to help you work through the exercise. The column “Unique because” is especially useful here: for example, two young men who both use wheelchairs will be as different from each other as they are from you. Perhaps one of them is musical, and the other likes a beer... What else makes them unique? Make notes.

## Caring for People with Physical Disabilities

**Exercise Part Two:** Look at the columns stating what people are able to do and what they cannot do (“Able to...” and “Not able to...”). Then ask the question, “Says who?”

For example, a baby is born blind. The family and professionals say that he will never be able to go to school or take care of himself: washing, dressing, cooking, cleaning – all the tasks needed to live independently. But there are blind people who do all this and more – going to university, having a career, getting married and raising children. Technology often helps – but even more important is a family that says “You can do these things and we will help you.”

**Exercise Part Three:** Look again at the people on your list – with each of them, is the disability central in your thinking or are you beginning to put the person in the centre? This is the first step towards Person-centred Care.

### 1.2. Understanding individuals as part of groups

**Groups are important.** If a group is big enough and has organised ways in which it can be heard, then it can make sure that it is included when services are planned. Here are two examples:

**Example»** *In countries in the North, new shops and government buildings are required to have “disabled access” – this means ramps and lifts for wheelchairs, notices in Braille for blind people, etc. And it means that the shop gets checked occasionally to make sure that the disabled can get in (and whether, if a fire started, they could get out).*

**Example»** *When a village in the South plans a new well, it should remember that about one person in ten has a disability. Within the village this group should have a voice. When selecting the site and the technology, it is important to bear in mind that the disabled villagers should also be able to use it.*



### 1.3. Understanding individuals as part of families

In the South, the care available for people with disabilities is often limited. In practice, it is usually carried out by the families of those in need. And, most often:

**Care = mother or daughter-in-law.**

Sometimes this care is impressively good and loving. Sometimes it is woefully poor.

**Example»** *A colleague was a trained Community Worker with a husband, kids and a full-time job. But both her father and her father-in-law lost their wives. Neither had learned to look after themselves. Their families moved them in with her. In the end she had to give up her own job in order to be their carer.*

## Caring for People with Physical Disabilities

Some people say that family-based care is the best possible model. But sometimes it is given at the expense of somebody else. When you hear someone say how good it is, ask whether the speaker is him- or herself caring for anyone at the moment – every day and every night?

### EXERCISE: UNDERSTANDING THE FAMILY SITUATION

Select two of the clients from your list and consider how they fit within their family.

- Financially – are they earners or consumers of family resources?
- Emotionally – are they constantly draining energy from the family or do they themselves radiate positive emotional energy, or both?

## 1.4. Understanding individuals as part of Communities

The Disabled may be part of a community consisting of those who share their Disability. Within such a group, the disabled person is able to feel equal – more able to do what they want, what they feel comfortable with, without having to contend with ‘normal’ expectations.

### **Example»** The Deaf Community:

*In the North, this is one of the most positive examples of how awareness has been raised.*

*For the Deaf community, “deafness” with a small “d” is a medically defined, negative condition which Society sees as something to be managed and treated.*

*But “Deafness” with a big “D” is different. It is the positive experience shared by members of the Deaf community. This community provides them with identity; it has, for example, developed its own ways of using technology and its own literature. A central feature is communication by signing. Lip reading on the other hand comes from the hearing community who want the Deaf to fit in with them. For some Deaf people, cochlear implants – which move children back into the hearing world – are seen as undesirable for the same reason.*

A disabled client may well be able to become a part of other local communities that consist of all kinds of people. As their carer, you may be the person to help them do that.

**Example»** *In West Africa, people often move from small inland towns to big cities on the coast, looking for education or work. The older migrants form groups to maintain their own identity and look after the younger people – they realise that students, including disabled students, can get into all sorts of trouble. Such groups provides social contacts, guidance and even small loans when necessary.*

Another type of community is faith-based. Make sure that if you introduce a client to a church/temple/mosque that it is a suitable belief system and sub-group for that person. Within each of the world’s big religions there are sub-groups with different beliefs and practices. Some are inclusive – welcoming everyone. Some are not. The client needs a proper choice about joining or leaving.

The right sort of community group, one with a compassionate leadership and inclusive culture, can provide a useful social structure in addition to spiritual support. Being part of an inclusive group of people who “care” in the wider sense can give an individual a strong feeling of worth and belonging.

### 1.5. Ensuring your clients' Human Rights

One way to look at caring is through the lens of Human Rights. Your clients, like everyone else, are entitled to basic rights and freedoms. It is important for them to be aware of these. If they are not, this is also an infringement of their rights. One way care workers can help is to point out what they can expect and what actions, practices and treatments they can refuse to accept.

**The Human Rights** of every client include:

- the right to life
- the right to a good death
- the right to be respected
- the right to liberty
- the right to be treated in a dignified way
- the right to have their private and family life respected
- the right to be protected from danger and harm
- the right to freedom of expression
- the right to access a range of services and facilities that may benefit their health and wellbeing
- the right to be free from discrimination in respect of these rights and freedoms

Human Rights are now everywhere being taken more seriously and in some countries are legal requirements. For example, in some countries, all children, including the disabled, have the right to an education without discrimination.

You can see the full 'Universal Declaration of Human Rights' at:  
<http://usgovinfo.about.com/bldehumanrights.htm>

In addition, since 2007, there is a 'Convention on the Rights of People with Disabilities':  
[http://en.wikipedia.org/wiki/Convention\\_on\\_the\\_Rights\\_of\\_Persons\\_with\\_Disabilities](http://en.wikipedia.org/wiki/Convention_on_the_Rights_of_Persons_with_Disabilities)

This Convention gives people with disabilities full equality under the law. They have the right, for example, to live independently. And they have the right to an inclusive education at all levels of the educational system – a key issue for many disabled people.

Not every government has signed and some have not ratified the signing. Ratifying commits a Government to taking appropriate action – which costs money. This commitment may come as part of a bigger agreement on receiving aid.



## 1.6. Going further with Person-centred Care

### EXERCISE:

Look at the client spreadsheet that you are completing. Choose one of the people on it and ask:

- When did their disability start?
- Did it develop suddenly or slowly?
- What was the individual's age?
- How did they see themselves beforehand? How did their parents see them?
- And after?
- Did they blame anyone or anything?
- What new behaviours were started? What stopped?

Think of the disability as a second character in the story of each client's life, and ask:

- What is the relationship of the individual to their disability?
- Are they comfortable with it? Resigned to it? Angry? Proud?
- And how do they see their future with their disability?



## Section Two: Learning More

### 2.1. Training and educating yourself

It takes a lot to become a better carer. This Section has some suggestions to help make it happen – how you can strengthen your abilities and find ways to learn.

You can learn **more information** – about your clients, the available services and the possibilities. You can do this by reading, discussing and thinking.

You may identify certain **new knowledge and skills** that you need. You can learn by practicing, either to strengthen existing skills or to learn new ones from scratch.

And... you can learn about **the attitudes that you already hold** – some may be mainly useful but some are perhaps damaging. You can do this by carrying out a **self-analysis**.

#### EXERCISE: ASSESSING ATTITUDES

Imagine you are a person who usually knows best. When a client has a problem, you do not take the time to look up your books or talk to the family or colleagues – you know what is right and you just tell the client what to do. You think this approach is best because if you are confident the client will be confident and trust you more.

Ask yourself:

- Is this a good set of attitudes to have? Would you like to have such a colleague?
- How much do you have in common with this person – a lot or just a little?

You can begin to question your own attitudes by slowing down, thinking twice, and checking with others – especially your clients. You can discover, and gradually relearn, whatever needs to be changed.

#### EXERCISE: CHANGING UNDESIRABLE ATTITUDES

Here is a the point of view of a client in Southern Africa:

*"I think it is very important that Carers have the right Attitude. I come from a country in Southern African and I have epilepsy. Sometimes I need help from the local Health Centre or Social Services. But I do not like going and I hate returning even more. The problem is the attitude of the staff. They make us clients wait for a long time and then they come and complain about how busy they are. They say how hard they have to work and how little they are paid. This may be true, but why tell me? I cannot help. They should complain to their bosses. And they hang around talking instead of getting on with the job. When it is my turn, they act as if I am a rubbish person. They do not show kindness. Then they prescribe medicines which they do not have and cannot give me. If the medicines are in the shops they cost more than I have".*

- Can you identify **two** attitudes shown by the Carers that need changing?
- What could be done to change them?
- Now make a note of attitudes that *you* have which are positive. And those which are negative.

### 2.2. Finding 'helpful friends' for further learning and training

One way of upgrading your skills is to form a **Support Group** of carers who are prepared to meet regularly and help each other. Work out a few rules to ensure client confidentiality, (e.g. 'what is said here, stays here'). You could then discuss the clients you are helping and the problems you are meeting.

This kind of group is particularly useful if you are working with an issue for which there are few resource materials available. For example, you could be working with someone with Down's syndrome and an elderly person who has had a stroke – other carers may be working with these same issues in your district. Ideally, you could all meet up regularly and each have insights and approaches to share.

Another way of upgrading knowledge and skills is through a **computer**. Find one that you can use regularly, perhaps once a month. Try the Public libraries and Internet Cafes. Visit and read **websites, newsletters and manuals**.

#### **Example» Internet research:**

*One of the writers of this manual wanted to research the following topics on the internet: Downs Syndrome, old-age dementia, and palliative care (the care of people with incurable disease).*

*There were good websites and materials to be found on all three but the information about services is very biased towards the North. One Palliative Care website, however, ([thewpca.org](http://thewpca.org)) refers to services in the South as well as the North, with materials translated into a range of languages. It has resources that people from Africa or Asia could use, such as the websites of regional branches, online training courses and seminars. This kind of site is very useful.*

You may (if you are lucky) find **online training courses** such as those for palliative care. Currently, these are almost always aimed at people in the North. For example, there are some in the UK that are specifically for people working in the country's National Health Service. But online courses are likely to become increasingly available in the South.

### 2.3. Support group learning activities

#### **EXERCISE: MAKING A DATABASE OF RESOURCES**

Find out and write down every local individual and institute that can help people with a disability – physiotherapists, schools for the blind etc.

If you use a computer, or cards stored alphabetically, you will be able to retrieve the information fast when you need it.

#### **EXERCISE: SEPARATING THE DISABILITY FROM THE HUMAN BEING**

In the group, share information about the clients you work with. Start grouping them according to the disability involved.

You will see that the same disabling condition can be more or less severe. Consider how generalisations can be very unhelpful.

## Caring for People with Physical Disabilities

### EXERCISE: THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY & HEALTH (ICF)

This is another way of sorting people into groups, by looking at nine broad domains of functioning that can be affected:

Domain of functioning	Yes	Partly	No
1. Can the individual learn and apply knowledge?			
2. Can s/he carry out general tasks and demands?			
3. Can s/he communicate with some or all groups?			
4. Is s/he mobile?			
5. Can s/he care for him or herself?			
6. Can s/he manage domestic tasks like cooking?			
7. Does s/he have personal interactions and relationships?			
8. Can s/he manage major life areas, such as education and employment?			
9. Is s/he active in the community, social and civic life?			

- Choose one of the clients on your list and write in how (s)he scores using these criteria. The answers will help you to work out with your client whether his/her expectations are set too high or low.

## 2.4. Viewing from a client's perspective

### **Example»** Adults with disabilities in Uganda:

*A snapshot was taken of disability in Uganda by interviewing a number of younger adults, male and female. The group is not typical of all the disabled, because they have all had a formal education and most are now working. Several work with other disabled people but one, for example, is an accountant. They painted a picture of what it is like to be one of the more fortunate disabled in Africa. And they gave witness that life is much worse for those who miss any chance of education.*

*Several of them remembered how it felt when the illnesses came that disabled them. One deaf respondent said "I found it so difficult to accept that I won't be able to hear sweet music any more". These memories increased their drive to achieve a good life.*

*The cause of their disabilities were common childhood illnesses - polio, meningitis, mumps and measles. But several respondents were from communities that use other concepts such as witchcraft to explain their condition. They found this really stigmatizing. One boy, on his first day of school, watched all his classmates run away in fear. Others found that their sudden disability led to the loss of friends and even*

## Caring for People with Physical Disabilities

*relationships with family members. That was hard to live with. But one respondent said "I'm respected by my former classmates because I defeated them in exams"!*

*The most important factor in their lives was that they got an education. And one common feature was having strong, battling mothers. These ladies would not give up, looking for ways to get them educated even when the schools were unhelpful. One mum taught her son all the domestic chores so that at home and later on he would not be dependent on others. Another mum whose son had polio learned from the elders how to massage his legs with local herbs. Which helped.*

*A lack of flexibility in the school system was a common problem. When they were small, specialist schools were not available. One boy with no working legs or wheelchair had to crawl to school for a time. One deaf lad had a cousin in the same class and got his education second-hand from him. In addition to the daily battle to get educated, they had to deal with children who could be really nasty in reaction to their being different. All experienced serious exclusion and teasing from classmates. One said it "decreased my happiness". And in adulthood they continue to experience discrimination – the most common assumption being that if they have physical problems they must also be mentally backwards.*

*They have problems as well with leaders in the Government and in the Disability world. They feel it is important to fight for education within the normal school system rather than through special schools – for mainstreaming rather than separate treatment. The group wants its political leaders to get better educated: for example, some leaders do not "see" deafness – being more invisible, it gets allocated fewer resources than lameness or blindness. Several deaf respondents saw themselves as having special problems because people assume they are "normal".*

*This group has reached adulthood after a childhood involving very hard work. "Living with a disability is not something easy. You have to make every deliberate effort to live a normal life. Attitude is everything". They seem to have a very strong sense of dedication to the service of their country, and have been able to form a network that is a small powerhouse of activity. Other countries would be lucky to have the same.*

The following exercise is for members of the Support Group to **improve their own attitudes and skills** in talking to clients:

### **EXERCISE: PRACTICING GOOD COMMUNICATION**

To prepare for this exercise, print out the Role-plays and the Interviewing Checklist\* from Section Six of this manual. (Later you can add to these role-play stories by coming up with situations from your own work).

- Select a role-play at random. Split into two groups.
  - One group chooses and supports the carer, who is meeting the client for the first time.
  - The other group represents the client, choosing who will act the role and deciding what they will say and what they hope to hear.Can the carer make the client feel important, central and with a voice in the decision making?
- Over time, do more role-play interviews. One of the group takes the role of client and one the role of client. The others are observers, filling in the Interviewing

## Caring for People with Physical Disabilities

Checklist. A good interview should score at least seven ticks out of ten (all ticks are positive); should anyone not perform so well in the role of carer, they can go on practicing until they do.

\* The Role-plays and the Interviewing Checklist are taken from “*Interviewing & Counselling at the Grass Roots*”, available in English, French, Arabic and Somali from the Networklearning library. The factors covered by the checklist are discussed further in this manual. If the Support Group needs to go back to basics it is recommended to download this title and refer to it for guidance:

[http://www.networklearning.org/index.php/library/cat\\_view/45-interviewing-counselling-at-the-grass-roots](http://www.networklearning.org/index.php/library/cat_view/45-interviewing-counselling-at-the-grass-roots)

There may be **extra factors** at work that hinder good communication, for example:

- a limited ability to use language effectively
- medical conditions such as cerebral palsy, which affect the client’s ability to speak
- memory loss, affecting a client’s ability to understand.

If someone does not speak clearly, people tend to think that they understand nothing at all and have no opinions. Here are ways of helping you work better:

1. Spend time listening
2. Ask different questions to get different replies
3. Talk to a speech therapist about your client
4. Talk to your Supervisor or Support Group

Sometimes the client goes back to speaking in their native language. So you may need an interpreter. For deaf people, you may need signers.

Talk to the client using **open questions**, not leading questions. Ask ‘How did you find that leaflet I gave you?’ rather than ‘That leaflet was great, wasn’t it?’

Questions that lead to “yes” or “no” answers are closed questions. Discussions where the carer talks much more than the client are closed discussions. If you take an open-ended approach to a discussion, the information you gain will be much more useful. And you will have shown respect.

### **EXERCISE: PERSONAL EXPERIENCE**

**This manual has referred to the way that people may treat the disabled as less than human. If you and your Support Group feel brave enough, you can experience this for yourselves.**

- Split into groups of about three people.
- Borrow a couple of wheelchairs and a couple of white sticks so that each group has one or the other. The people sitting in the wheelchairs need rugs or cloths over their legs. The “blind” people with the white sticks need dark spectacles smeared with grease or hand cream so that their eyes are not visible and they cannot see well.
- Each group goes to somewhere fairly crowded where the “disabled” person can ask for help – e.g. to a college, where the “disabled” person asks the way to the admissions office; or to a market where they seek a specific item. Or choose some other similar situation.

## Caring for People with Physical Disabilities

- Meet up later and compare experiences. Note how often the “disabled” person was treated – was(s)he properly listened to or ignored by people answering questions?

### 2.5. Supervision

Good supervision helps you gain better skills. If you work for an NGO you would normally have a Supervisor. Some are real and active but some exist mainly on paper. You can ask for more supervision. You can ask to be supervised by somebody with a good reputation. If all your efforts fail to get results, you can look outside for your own 'mentor' – i.e. somebody more experienced who can give guidance, for example a carer who is now retired.

**Suggestions for Supervisors:** You may already be a supervisor or may be one in the future. Ideal supervisors do the following:

- Spend the right amount of time with their supervisees (those supervised)
- Praise what the supervisee does well
- Point out what needs to be improved and how to do better
- Are realistic when writing reports, since reports play a role in promotion

### 2.6. Caring For the Carers

The job of a carer is hard. Most jobs in the caring professions are very taxing and poorly paid (except for doctors). Carers draw from their own emotional capital every day. They may say that they get their reward from seeing people who are being helped and whose life is improving. But some fields are more “rewarding” than others. For example, consider the effects of working with the dying (palliative care) over the long term. It is important that every carer learns to know themselves. They need to find out how to keep well emotionally, mentally and physically. They need to recognise the symptoms of burnout.

In addition to helping improve skills, a **Support group** can also play an important role keeping its members in good health. Members can tell each other how they are doing and feeling – though it may be important to limit the time spent expressing troubles or the group will go away depressed.

It is also important to discuss ways of keeping physical and mental balance. Everyone needs to find ways of sleeping well, eating well and keeping their private life alive and healthy. Some people might find meditation or yoga useful. Some carers have a little ritual halfway between leaving work and arriving home, when they stop for five minutes, puff out their frustrations and in their minds shut a door on work.

### 2.7. Family Carers

In any family, at any time, a tragedy may strike – someone may have a stroke or a car accident; or a baby may be born with a disability. The family tries to respond and, usually, one person takes on the key role of organising the care of the newly disabled relative – (s)he becomes responsible for making sure visits to doctors or physiotherapists happen; for organising the daily care involving food, washing and clean bed sheets; for being the source of stimulation and encouragement.

## Caring for People with Physical Disabilities

Now the family has a carer, whose life has been turned upside down. For many of these, playing such a huge new role is overwhelming. Some say that it is like a lifetime prison sentence – but they will not say that in front of the person with the disability. They develop a public face for everyday show – and a secret face which they only show from time to time.

### **Example» Advice for Family Carers:**

*The following Advice List is given out to family carers who use a General Practice in Australia. The Health Workers there had seen how demanding and difficult the Caring role can be:*

- *Maintain your relationships with your friends and society*
- *Be prepared to put pressure (in the nicest way) on the cared-for to help themselves*
- *Accept help without assuming you have an obligation. Those who have helped you will be helped in their turn. Use all the services available*
- *Tell your helpers, if necessary behind the cared-for's back, exactly what the situation is – without exaggeration. Especially tell people when the cared-for has pain*
- *Accept respite (taking a break) from care. You MUST have time out - half a day in every week, a week-end in every month, a week in every three months. You must go away to where you can truly relax – not necessarily with your family*
- *If things are going wrong with your support, seek an outsider to discuss the problem (mediation). Do not let things go too far*
- *Look on the bright side, smile and see the humour in the situation. There is usually a bit somewhere! Admit to yourself that you are under stress. Do not worry if you get upset: we know how much stress you are under*
- *Look after your own health*
- *Keep your use of helping "substances" to a minimum. This includes caffeine, nicotine, and of course alcohol; but especially it means sleeping tablets, which should be used a maximum of once a week*
- *Make sure you get sufficient sleep. These things may help: keep your use of helping substances to a minimum; have your main meal at midday; relax before bedtime with no TV news or violent programmes; take only short naps in the day time*
- *Exercise regularly: do something every day*
- *Lower your standards to conserve time – for example do less house scrubbing*
- *Know when it's time to bail out – to stop.*

Remember that children can be carers too:

**Example»** *Naomi is seven. Her mother has a form of rheumatoid arthritis which means that walking is really difficult and painful. Naomi's father has disappeared. She started taking care of her mother as soon as she learnt to walk and talk. Every day, before she goes to school, she helps mum go to the toilet, wash, dress and sort out her medicines. School is legally compulsory but Naomi slides out early when she can. She shops on the way home. They eat mainly sandwiches or potatoes and porridge which she can cook. She misses after-school activities and does not have enough time for homework. She and her mother are terrified that if the authorities knew of their situation they would take Naomi away. So both are hiding the situation.*

## Section Three: The Work of a Carer

### 3.1. What people need – and whether services are available

Whether or not we have a disability, we all have physical, intellectual, psychological and social needs. Life is partly about finding ways of meeting these. With clients, some needs can be met from within their own psychology or by the people closest to them. But they usually have several unmet needs, too. Some of these needs can be met by services.

**The range of Services:** In better-off regions of the North, among the services you might find are:

- support groups for clients and their families
- paid home cleaners
- social and sporting clubs
- centres that provide day care, respite care etc.
- providers of telephones
- services that provide meals
- HIV care kits
- laundry services
- accessible transport
- home adaptations or insulation services

**Building up your own district-wide list of services & resources:** Many of the services listed above are likely not in place where you live. A client is lucky if they live in a region with more than a few basic services. Sometimes the lack of one service makes other facilities unusable, for example if there is no transport to the service provider or it requires an interpreter. In regions in the South there may be hardly any services.

You should have a broad understanding of what services and facilities are available in order to inform clients. And you need this later when clients require information and encouragement to take the next step. (See the first Exercise in Section 2.3)

If you work with an NGO and are faced with a need but there are no services, you can consider these possibilities:

- to support services managed by those involved – for example, pressure groups set up by the parents of disabled children and self-help groups for people recovering from mental ill-health
- to start services yourselves
- to support Advocacy groups
- as an individual, to find creative solutions within the family and neighbours



## Caring for People with Physical Disabilities

### 3.2. The need for employment and income

Sometimes it is assumed that people with disabilities cannot work. But work, meaning involvement in something productive, is an important need for most people.

Think of those you know who have had to stop with their job – perhaps a male who reached retirement age; a mother whose children left home; a gardener who had a heart attack...

Most people find it difficult when they have to stop against their wishes. So think how hard it would be if nobody even lets you start.

**Example» Attitudes to People With Disabilities (PWDs) and employment:**

*Unemployment contributes greatly to the low self-esteem of many PWDs. Many employers look at disability as a “disease” to be cured. Potential employers think of PWDs as special people who would need special arrangements in the workplace. These are bound to cost money, so it is safer not to offer jobs.*

*In reality (depending on the nature of the disability), PWDs only need acceptance and a good working relationship with their colleagues. Getting to this point is helped by mentorship and guidance, and perhaps a few adaptations such as ramps for wheelchair access, computers with the right programmes for people with visual problems, or, in some cases, sign language interpreters or personal assistants.*

*In return PWDs have a sea of experience in meeting challenges that they bring to the work place.*

**Example» Employment from within:**

*In the South, most PWDs are non-literate and cannot find employment. Many are at the edge of poverty. So we thought hard about the alternative of self-employment. We developed a recycling project which now employs over 150 people with disabilities. They collect recyclable plastic from all over – homes, schools, trading centres – and bring it to the collection centre where they sort and clean it. It is then chopped into small pieces to be sold to Kampala recycling companies. PWDs are assured of payment for their work and thus have an income.*

### 3.3. The need for mobility

Every client needs mobility. Within their home, this means moving from kitchen to sitting place to bed.

Paraplegics in wheelchairs often need to build muscles in their upper bodies to compensate for loss of strength in their lower bodies. They can use their arms to move their chairs, lift themselves from chair to bed, play sports etc. If they put on excess fat, rather than muscles, all these movements become more difficult.

For the Blind, mobility means finding their way from house to house, from home to work. Currently in the North two aids are widely used: blind people use a long stick and use it to feel what is in front of them. It is used in combination with learning the route – they think for example “after twenty-three steps I reach the corner. The cane will tell me when I get to the curb. I wait for the street light to start making beeping noises which mean “cross”, then I start walking”. In addition to the cane, there are trained guide dogs.

## Caring for People with Physical Disabilities

### **Example» Guide Dogs and Islam:**

*In Leicester, UK, Mahommed, who is 18 and blind, was recently assigned a trained guide dog. This means he can now attend college. But his mother cried for two weeks at the thought of a dog in her house – dog saliva is seen as dirty. Also the dog could not go into the mosque. There was a lot of discussion; finally the Sharia Council of the UK passed the first fatwa to allow a guide dog into a mosque. He can now come in as far as the area where worshippers' shoes are stored and can wait there during prayers. And Mahommed's mother has seen the difference the dog has made to her son's independence and feels OK about it.*



### **3.4. Physical exercise**

People need to work at staying fit as they get older and almost every client needs to have exercise in their care plan. Their body needs to stay mobile to keep healthy – and vice versa.

Following an illness or accident, a healthy body will speed the recovery process and help maintain a positive mind. And a positive mental attitude will help the physical recovery...

Clients may need to start with physical exercise. Within any group, different physical activities can be identified and supported. However, some clients may be unwilling. Think of ways to encourage them to give it a go. For example, if clients can participate in activities that make them feel good, they are more likely to continue. Often this means an activity that is familiar – e.g. a local dance session that they have been attending for decades – and/or one with a social as well as a physical aspect – e.g. after the dancing everyone enjoys lemonade and gossip.

Strength and stamina can be built or maintained by, for example, swimming, using weights or riding exercise bikes. Carers can develop local methods that make expensive equipment unnecessary: e.g. tins and wooden bars can be used for weightlifting; a normal bicycle can be anchored on the ground.

Some elderly people may have little mobility and need all that they have – so that they can continue to move around their home, make tea, open the door for a visitor or use a phone. A programme of gentle stretching exercises which could be done while sitting is a good start. This could then progress to other activities such as short walks.

Different activities contribute in differing ways to a person's level of fitness. Find out about activities and gentle exercises that can benefit flexibility and suppleness, heart functioning, improved digestion, better sleep, hand-eye co-ordination or breathing. In particular, there are yoga practices that can help with all these plus all-round mental and psychological health.

### **3.5. Devices that help**

There exist many devices (technology aids) which are low-tech, cheap to make and effective for enlarging the range of activities that disabled clients can resume. Your Care Plan should include research into what is available, or can be improvised, in your region.

## Caring for People with Physical Disabilities

Bear in mind there may be hidden dangers to the client. For example, a bed ladder hoist is very useful for someone who needs a small amount of support in order to come to a sitting position. But carers must be vigilant and aware of pressure sore areas. Sores can happen as a result of individuals using items such as bed ladder hoists with nobody checking.

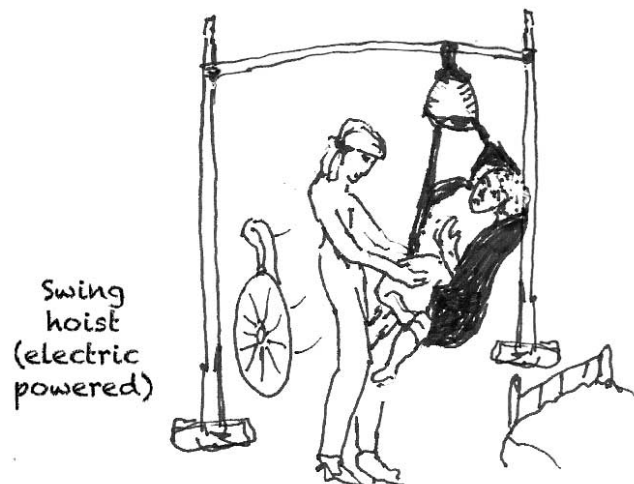
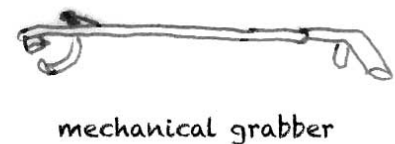
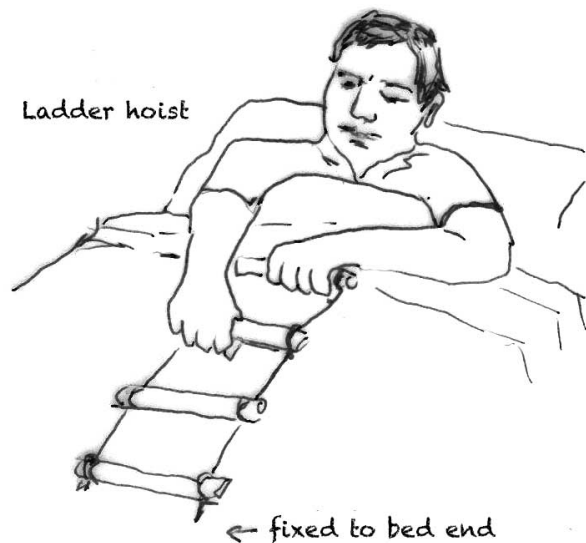
Another example is a “grabber”. Check that clients can stay balanced when they use one.

Devices or aids remind carers to think of other factors:

- A device needs to be checked regularly to make sure it is not broken or worn.
- It also needs to be checked to make sure that it still matches the client's needs. Clients change over time. Some get better and some get worse. Perhaps, after a time, using the grabber stops the client from using his hand enough. So the Grabber may then need to be put away.
- Another factor is cleanliness. Not only the devices but the surroundings of the client need to be cleaned regularly.

Some devices are extremely useful yet quite difficult to use in practice. For example, a ceiling hoist – which is based on a simple idea even if the types used in the North are technically complicated – can be used to swing someone in and out of a chair, bed or bath, or even to help get someone using their feet. It is very important, with this or indeed any device, that carers take the client's role at least once – and use the hoist (or a bed ladder, grabber etc.) themselves in order to experience what it is actually like for the client. In doing so they can feel some of what it is like to be cared for. It is a way of putting themselves in the shoes of the people they work with.

Too often, when disabled clients are asked what it is like to use a device, they say that they feel helpless and ignored, or treated like a baby or object. If they are in a wheelchair or a hoist, people talk across their heads, as if they are invisible. They can be bumped around as if they have no feelings – even tipped until they are at risk of bruising or falling. It is a big lesson if carers can go through the experience of being handled by others – and allow themselves to feel out-of-control and helpless.



## Caring for People with Physical Disabilities

If a carer really goes through this, they will be more effective in building the confidence of a client when a new aid is introduced. Carers need to explain the actions they are going to carry out – for example with a hoist – and explain it to them again every time they carry out a transfer. The client can be asked to participate, perhaps by leaning in the most helpful way. This gives a nervous individual something on which to focus.

**Digital devices:** In parts of the world, mobile phones are becoming the technology that blind people find the most accessible and usable. However, computers still perform tasks that most mobile phones cannot. There are computer programmes that read text aloud and others that turns the user's speech into written text. For all these technologies, cost remains an issue.

### 3.6. Good record-keeping

Records need to be kept of each new development – for example, when a client agrees to a change in their care. To make a suitable record, you could:

- record a summary of the client's comments and ask them to agree that you have recorded their views correctly and accurately.
- provide feedback.

Keeping records helps keep the client central and ensure that:

- you, the current carer, remain actively involved with the client.
- the client knows that his/her opinion was important and was written down.
- any future carers will know what was agreed to.

Records should always be:

- readable.
- authenticated (with date, time and signature).
- accurate, with factual data.
- relevant and truthful.
- complete, with full details of care and treatment including identified risks.
- protected, with measures taken so that confidentiality is maintained.
- original; any alterations must be signed and dated.

**Records and literacy:** When programmes are set up, the organisers often want records to be kept in a certain format. But sometimes this means that they insist on workers who are literate. They should therefore consider the following:

- In many countries, insisting on literacy may screen out the poorest and most women – who may be the groups that the project most needs to involve.
- Record keeping systems using pictograms have been developed and used effectively by non-literates.
- Non-literate workers can be obliged to find a literate helper – e.g. a relative or neighbour – who can help them fill in key information.

## Section Four: Making and implementing a Care Plan

What follows should be considered a guide only. Your own Care Plan might look very different. Look at the following sections and, with each, ask whether it is relevant to your clients – and if so whether it is covered in the Care Plans you are currently using.

### 4.1. Coping with a diagnosis

A generation ago, certain conditions, such as cancer or syphilis, were barely mentioned. The hospital may have informed the family of the condition, but did not tell the patient. Now everyone agrees that clients need to be informed about their diagnosis, even if it is bad news. They have the right to know.

In your culture, what are the words that continue to carry great fear? How would you respond if you were told you have schizophrenia... cancer... polio... a severed spine...?

Imagine that a family have just been told some bad news – how can you help? The first thing you can always do is take time to **listen**. You can sit in silence, making sure you have an open posture that encourages communication.

The family or client may have an initial reaction that includes one or all of the following:

- shock
- anger
- denial and a refusal to acknowledge the issues
- fear of losing home, friends, dignity, privacy
- demands for more information about the condition, its symptoms, treatments and long-term outcome
- tears and no words
- requests to family/friends for emotional support

Where the family are also the carers the reaction can be even stronger. You as a carer may also experience strong reactions.

After listening, your next role as a carer from outside the home is to accept every reaction and be supportive. There will be time tomorrow to get realistic. Clients and others will make it clear when they want to hear more. They will start looking for a better understanding of what is happening; they will start planning for the future.

### 4.2. Setting reasonable expectations

The client and family have started to accept the diagnosis. Now there needs to be a period of discussion.

What are the future possibilities and difficulties? Perhaps the client has to accept that independent living is in doubt – that it will not be possible without a lot of help and money.

## Caring for People with Physical Disabilities

Perhaps the only source of help is a relative they dislike. These types of issues need negotiation. A spirit of good will needs to come in.

Another issue that may come up is that you, the carer, think you know what is best but the client has other ideas.

### **Example»** A colleague from the field wrote:

*“Miriam is a 38-year-old Iraqi. A suicide bomb made her a widow. She has arthritis and it's difficult for her to move around. She lives mainly on the money earned by her two older boys who do casual work. When our NGO became involved she was very happy with the financial support we could give her. We tried to get her to enrol in our computer training course. It is designed for people like her and she is certainly smart enough to follow it. But she has got comfortable with her life and with the role of victim, with prayer and gossip, even though the family have very little. Now we are talking to her about her responsibility to get her three smaller children into school – which means finding a job. So perhaps now she will start making changes”.*

**Problem analysis:** Once the carer and client have sorted out what are the “reasonable expectations”, a thorough “problem analysis” should be done. This will support the creation of a practical Care Plan. The problem analysis takes into consideration the total reality of the client’s problems and what is possible within a specific culture. But it never forgets that at its centre is the client’s identity – a unique set of needs and abilities.

### **4.3. Setting goals for the Care Plan**

The goals you set will depend on the individual and their problems – so involve the individual when deciding these goals. Everyone has the capacity to make their own decisions until proven otherwise.

#### **Example»** Goals:

*Irma is a middle-aged woman living alone who has had a stroke. This has affected her right side and she has difficulties with household tasks. The hospital physiotherapist says that if she follows a programme of visits and does certain daily physical exercises on her own, she will regain ability. She also needs a diet with fewer calories and less fat to reduce the risk of another stroke.*

*Irma and her carers together set the following goals:*

**Overall goal** – to help Irma stay independent, by:

- 1. preventing further strokes*
- 2. helping her regain hand skills, and*
- 3. helping her get fitter by exercise and diet*

**Specific goals:**

- 1. to ensure Irma attends all the physiotherapy appointments by having her family arrange the transport*
- 2. to make her kitchen as adapted as possible to her limitations*
- 3. to find ways for her to exercise regularly*

## Caring for People with Physical Disabilities

4. *to keep central her position as a loved and visited aunt*
5. *to make a month-long meal plan that includes some meals cooked by Irma plus others that the family bring in. The meals have to suit Irma's taste but help her lose weight*
6. *to discuss with the family how to support Irma in caring for herself – not to take away her abilities and independence*
7. *to keep her in control of when and what she eats*
8. *to ensure that any support planned does not burden just one family member*

*When Irma returns home she will find cooking tricky with only the one hand working properly. The potatoes will be badly peeled, the kitchen will be messy. But the family and carer must not move in and take over. Irma will get more skilled. She wants – and has the right to – independent living, as part of her human rights (see Section 1.5).*

### 4.4. Agreeing responsibilities

The client should be encouraged to take as much responsibility as possible for their access to services and facilities. You should also agree on the extent to which the client has responsibility for any activity that is planned. The family, if there is one, should also be involved in order to decide their share of responsibilities.

Carers need to be aware all the time that they should not take on a responsibility that someone else could do. Most carers are overburdened to start with. In addition, it is not in the interest of the client to do things for them which they could do themselves.

### 4.5. Awareness of barriers to using services

There are various kinds of barriers that can often prevent clients using services that are available. The individual may need help with strategies to overcome them. They include:

**Physical barriers:** stairs; lifts whose controls are out of reach; lack of ramps or adapted toilets etc.

**Technology barriers:** computers or other technology; lack of confidentiality for information communication etc.

**Psychological barriers:** fear of losing independence; anxiety about being cared for by others; a perceived stigma; services delivered in a patronising way etc.

**Barriers associated with mental ill-health:** unreasonable fear of authority or discussing personal information etc.

**Financial barriers:** charges/fees; lack of transport; too great a demand for a service, so no room; under-resourced services whereby insufficient money/staff to support the service, insufficient information about services etc.

**Social & cultural barriers:** discrimination; social exclusion; language barriers, e.g. services or information in majority language only; concepts about modesty; clients wanting care only from same-sex providers; treatments being unacceptable culturally.

## Caring for People with Physical Disabilities

You should have a broad understanding of what services and facilities are available in order to inform clients. And you need this later when clients require information and encouragement to take the next step.

### **Example» Overcoming barriers to using services:**

*Irma, the middle-aged woman who had suffered a stroke, did not want to try any form of exercising. She said she had never done any and would not start now – not even short walks. The carer had to work her way around this barrier and several others.*

*She tried to find Irma someone pleasant to go walking with but failed. Then she heard of a weekly exercise class based on gentle dance movements. She talked to the class giver who put her in touch with one of the participants.*

*This lady visited Irma, told her about the class and suggested she take her for a try-out session. Irma went and received a lot of encouragement. She liked the physical effects and the drink-and-gossip session afterwards.*

*Irma complained that the shower cubicle did not have a curtain so if she had wanted to take a shower she could not. The management said that the majority of clients do not demand privacy. Irma also complained that the class giver and most of the members were a different ethnic group (though they had a common language). So there were only a few women for her to gossip with.*

*Money for the class and for transport was necessary. The carer was able to get Irma's family to pay six months' subscription at once, together with the bus fares. A class member goes on the same bus that Irma would take and they agreed to ride together.*

## 4.6. Monitoring & Evaluating

Monitoring is a continuous process, something which you do whenever you visit a client.

You can regularly **monitor**:

- **the health, mobility and general well-being of all clients.**  
Any changes should be marked on a check card or otherwise put in writing. These changes might show good progress but might also show a decline.
- **progress towards the Goals that were agreed on when the Care Plan was made.**  
If Goals are practical and measurable, they become very useful. With the elderly Irma for example (see Section 4.3), one Goal was “*to keep her in control of when and what she eats*” – this is something you can monitor easily on a visit with just a few questions.

As well as monitoring you need to carry out **periodic reviews** – from time to time, step back from each client and take a long view of them, their home and their aids/devices. Is it time to change and adapt? Or is everything going well? Are you sure that everyone is getting the best help available?

**Evaluating** needs to be done less often but is just as important. In an evaluation you refer back to the Big Questions:

- Did we set the right Overall Goal?
- Were the smaller goals well chosen for achieving this Overall Goal?

Or did we, for example, plan an Overall Goal of Independence and then build a bunch of activities that took away all the client's responsibilities? Perhaps circumstances have changed



## **Caring for People with Physical Disabilities**

and we need to rethink. Consider whether all the goals are still valid and whether it is time to adapt one or more goals.

### **4.7. Saying goodbye**

Some of your clients will need help for the rest of their lives. But some, after a time, will no longer need you. This should be reflected in the Goals and the Care Plan.

With someone who has been operated on for cataracts, for example, this could be a goal: to help them until they are seeing and carrying out normal tasks independently.

If the client is reluctant to return to independence you could put a time frame on the Goals – to help them, say, for six weeks. When the time comes to say goodbye, it is worthwhile acknowledging that you have completed a task.

At other times you will have clients who die. Feeling sadness is normal. It is worth talking it over with your supervisor or support group.

## Section Five: Background notes

### 5.1. The politics of disability

**Most disabilities in the South are preventable:** The main underlying causes of disabilities are poor basic health and maternity services and poor provision of water and sanitation.

For example, cerebral palsy is usually caused by damage to an infant brain through prolonged labour – good trained midwives can often prevent this. Epilepsy is usually caused by untreated infections that leave scars in the brain tissue – good basic healthcare services can treat these infections with antibiotics.

**Disabled people in the South are most often rural, young and poor:** Therefore they have little political influence. Major provisions and prevention are very expensive. So politicians do little to help this group.

**Application of medical technology:** Both North and South have increasing road usage, accidents and resulting trauma. Both have armed conflict in official wars, unofficial uprisings and invasions. The medical technology available in the North will keep higher proportions of damaged people alive – disabled rather than dead. Disabled soldiers are a good example of a group seen as especially “deserving”. However the proportion of victims of trauma who are civilians and children is getting higher.

**Causes of disability are different in the North:** Most countries in the North have reduced disabling childhood illnesses. Disabilities there are mostly in older people whose bodies are wearing out – for example, a man aged over 60 who has had a stroke. He will most likely have had an education, worked and paid taxes, and still be voting. Such individuals are able to organise, sign petitions, form NGOs and help fund research and advocacy. As their lives are prolonged this can put huge demands on the country's health services.

**What people in the South can do:** Any group considering action needs to find out what their Government is doing regarding the ‘Convention on the Rights of Persons with Disabilities’ (see Section 1.5). Within that reality, start up advocacy that demands better health provisions for the rural poor in general, and – for the disabled – access to services and benefits that are more in proportion to their needs and rights.

### 5.2. Genetic causes of disability

The genes that form the blueprint of our human body can sometimes cause problems. They can alter (mutate) for the worse. Problematic genes – those that have the potential to cause disease – can get more concentrated in communities where close relatives marry. A disease which is dormant in one generation may become active in the next generation. For example, sickle cell anaemia and cystic fibrosis – both disabling and life-shortening illnesses – can be genetically inherited from apparently healthy parents.

In one Pakistani community studied in the UK, the rate of birth abnormalities was 3%, nearly twice the national average. In families where the babies had birth defects, 77% of the parents were close blood relatives. The babies’ abnormalities included heart and lung disorders and Down’s syndrome.\* Babies born to cousins are at higher risk of mental disability, too. Another group with a higher risk of passing on genetic defects is older child-bearers. These disabilities resulting from genetic factors are avoidable – by avoiding marriage between close relatives,

## Caring for People with Physical Disabilities

and by women preferably having all their babies before the age of 37. But such cultural change is not easy. It demands the involvement of religious and other leaders, plus the right kind of education and advice for people planning marriages and starting families.

\* “Born in Bradford” – Study of over 11,000 babies and their families:  
<http://www.bbc.co.uk/news/uk-england-leeds-23183102>

### 5.3. Carers and Gender

Factors linked to Gender are important in the business of caring. In most cultures, caring is seen as an activity belonging to women. Often, little girls are taught early on that looking after both girls and boys is part of what they do. Think of your own culture. Which children of secondary school age are the people feeding babies and old people, cooking for them, helping the bed-ridden... is it mainly boys, or girls?

A majority of the workers in the caring professions – nurses, physiotherapists, social workers – are female. The characteristics of these professions are:

- The workers get lower pay than those in other jobs which are male-dominated
- Men occupy many of the management posts
- The job does not have a lot of status. Consider how, in your country, nurses are regarded compared to doctors. Compare the political clout of the two professions

So, when the professions working in care need to bring about change for their clients, they may have to fight twice as hard.

### 5.4. Institutions that can help or harm

The use of institutions is increasing, especially in caring for orphans and vulnerable children (OVCs). Worldwide there are millions of children in institutional care. However “institutionalisation” – the damaging effects of long-term care in hospitals or orphanages – has been identified as one of the major factors holding back early childhood development.\*

Most individuals do better if they stayed in their **own family** – even if that creates problems; most normally functioning families have problems. If that is not possible, the next best alternative is **fostering**. Fostering is the placing of individuals in a caring family, under supervision, for which foster parents receive some payment.

Some **Institutions for the Disabled** play a positive role in caring.

**Example»** *A colleague became blind when she was three, after catching German Measles. She was sent to a residential Institute for the Blind when she was still quite young, aged seven. But she thinks that it was a good decision. She spent holidays at home, where the family looked after her with a lot of love. But they could not be tough with her. In the Institute she was trained to live by rules acceptable to the seeing world. For example, there was stress on using strict table manners. She became independent and was able to make her own mistakes. She left able to function in the seeing world. She went on to a college education and career and married. But... the Community (see Section 1.4) might say that the Institute took her away from the Blind Community and made her a second-class member of the “normal” community.*

\* See the journal *The Lancet's* series of articles on ‘risk and protective factors for early child development’:  
[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60555-2/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60555-2/abstract)

## Section Six: Resources and References

### 6.1. Hesperian Health Guides

One of the most useful group of materials is provided by **Hesperian** ([hesperian.org](http://hesperian.org)). This organisation develops and sells health guides but also makes sure that their materials can be downloaded for free by those who need them.

The following titles in particular are relevant:

- » *Helping Children Who Are Deaf*
- » *Helping Children Who Are Blind*
- » *Disabled Village Children*
- » *A Health Handbook for Women with Disabilities*

These can all be downloaded as PDF from Hesperian's 'Books and Resources' page at <http://hesperian.org/books-and-resources/>

### 6.2. Networklearning manuals

The following disability-related manuals are free to download from the Networklearning Library ([networklearning.org](http://networklearning.org)):

- » *Simple Devices to Assist the Physically Disabled* (also in Arabic & French)  
[www.networklearning.org/index.php/library/cat\\_view/52-simple-devices-to-assist-the-physically-disabled](http://www.networklearning.org/index.php/library/cat_view/52-simple-devices-to-assist-the-physically-disabled)
- » *We can play and move: ideas to help disabled children learn to move through play*  
[www.networklearning.org/index.php/library/cat\\_view/82-we-can-play-and-move-ideas-to-help-disabled-children-learn-to-move-through-play](http://www.networklearning.org/index.php/library/cat_view/82-we-can-play-and-move-ideas-to-help-disabled-children-learn-to-move-through-play)

Other useful Manuals in the Library:

- » *Finding Mental Health after Conflict* (also in Arabic)  
– this manual is written for workers in districts where there has been a war or natural catastrophe, and where no services exist.

[www.networklearning.org/index.php/library/cat\\_view/83-finding-mental-health-after-conflict](http://www.networklearning.org/index.php/library/cat_view/83-finding-mental-health-after-conflict)

- » *Interviewing & Counselling at the Grass Roots* (also in Arabic, French and Somali)

[www.networklearning.org/index.php/library/cat\\_view/45-interviewing-counselling-at-the-grass-roots](http://www.networklearning.org/index.php/library/cat_view/45-interviewing-counselling-at-the-grass-roots)

- » *How to Build a Good Small NGO* (also in Arabic, French and Vietnamese)

[http://www.networklearning.org/index.php/library/cat\\_view/41-how-to-build-a-good-small-ngo](http://www.networklearning.org/index.php/library/cat_view/41-how-to-build-a-good-small-ngo)

### 6.3. Further reading on issues raised

**Online training courses** (Section 2.2)

- » Article: *Free Online Higher Education*

[www.networklearning.org/index.php/blog/networklearning-news/221-free-online-higher-education](http://www.networklearning.org/index.php/blog/networklearning-news/221-free-online-higher-education)

**Record keeping and non-literates** (Section 3.6)

- » Chapter 7 of *Testing and Evaluating Manuals* (also in French)

[www.networklearning.org/index.php/library/cat\\_view/55-testing-and-evaluating-manuals](http://www.networklearning.org/index.php/library/cat_view/55-testing-and-evaluating-manuals)

**Genetics** (Section 5.2)

Genetics and heredity are aspects of biology that are not easy to grasp. Try these articles:

- » "What is Genetics?"

<http://www.news-medical.net/health/What-is-Genetics.aspx>

- » "Genetic Inheritance"

<http://www.news-medical.net/health/Genetic-Inheritance.aspx>

- » Wikipedia's entry at

<http://simple.wikipedia.org/wiki/Genetics>

**Institutionalisation** (Section 5.4)

- » Article: *The Orphanage Problem*

<http://phenomena.nationalgeographic.com/2013/07/31/the-orphanage-problem/>

## 6.4. DISABILITY ROLE-PLAYS

1. Boy, 13

*I lost my leg in a car accident. It was my fault. God must hate me. Now I spend most of my time in our hut. I mind the babies sometimes but my mother does not think I can do much. I could cook if she let me. Someone made me a wooden leg but it was painful to wear. I used to go out a bit into the village but they laughed at me so now I am happier in the hut.*

2. Boy, 15

*O.K. I am blind but why do they treat me like a small child? Why does my father say that I can do nothing to earn my living? I feel angry all the time. There must be things I can do. There is a school in the town and another blind boy goes there. He is going away and will train to read Braille. But I do not qualify – because I do not go to school.*

3. Girl, 17

*I lost both my hands playing near a landmine. I was fitted with one prosthesis (a plastic hand) and I have learnt to do housework. And I am a very good dancer. But the hand is no longer working. The Rehabilitation Centre got the hand from Europe and now they have run out of money and have stopped repairing prostheses. Housework is more difficult with stumps. And now my father says he cannot arrange my marriage – no boy will have me without a big bride price. I am pretty depressed.*

4. Man, 48

*They call me the Reverend. I, with my wife, have worked all his life in this community in East Africa. But I got diabetes and had a stroke. Now my speech is slower and one leg moves slowly when I walk. I remember so many times, over the years, when I have sinned. Mostly they were small sins. But sometimes I was greedy – for cakes and biscuits. Was the stroke a punishment? Should I take the pills the doctor prescribed - or refuse them and accept what God wants for me?*

5. Woman, 23

*I gave birth to a girl baby two weeks ago. She is floppy like she has something wrong with all of her limbs. I feel like a failure and guilty – I must have done something wrong during the pregnancy. Perhaps the baby could go into one of those Institutions. Or perhaps she was never meant to live. If she dies, I can start again and maybe this time get a son.*

6. Young man, 17

*I was in a diving accident last year. Now I have no feeling, no control below my waist. The doctors say that I will be in a wheelchair for good. I am angry most of the time. My girlfriend has left me. I don't think I will find another one now I am like this. My Mum and Dad are altering their house so that I can live with them and be looked after like a baby. It's a good thing Dad is rich. Or - this charity says they are building special flats where I could be independent. But it will be really hard work building my strength so that I can*

## Caring for People with Physical Disabilities

*move around and learning to cook and everything...It is NOT FAIR!*

7. Woman, 35

*I am worried. Duka, my great grandmother, lives alone. She had a stroke and one leg does not work well. She is also becoming forgetful and does not eat properly. She does silly things that put her at risk. I am the only family member still living in the same village. I have seven children. The family insists that one of them, Eela, goes and lives with her and looks after her. Eela is eight and very smart. She loves school and Duka would not let her attend. She thinks school for girls is a waste of time. I work all day in the market and we do not have any spare money. At least if Eela is with Duka there is money to feed them both.*

8. Teenager

*My sister got measles when she was ten and went blind. My mother does everything for her even washes and dresses her. She never goes out. Mostly she is quiet and sits in the corner. But soon she will be an adult and I do not think this life is right for her. My mother says she is keeping her safe and loved.*

9. Girl, 12

*I became deaf after mumps when I was eight. For two years I sat and cried. Now my father has found a residential school for deaf children and wants to send me there. But here I have my family who love me and with lots of hugs I can just about stay normal. I do not go to school. Away at boarding school I think I would get seriously depressed. I have heard about teenagers with disabilities who commit suicide. That could be me.*

**6.5. CHECK-LIST FOR INTERVIEWING SKILLS**

Did the interviewer do the following?	Yes	No
1. Welcome the client politely		
2. Use clear language		
3. Have good positioning and body language		
4. Ask good questions and listen well		
5. Show respect		
6. Sort out the main problems and priorities		
7. Give good information		
8. Be clear about who will do what		
9. Make a further appointment		
10. Say goodbye nicely		