

BEST PRACTICE GUIDELINES  
FOR IMPLEMENTING FAMILY-  
CENTERED CARE FOR CHILDREN WITH  
DISABILITIES IN THE NORTH WEST  
REGION OF CAMEROON

PREPARED BY

THE BEST PRACTICES IN FAMILY-CENTRED CARE GROUP

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## **Guideline Title**

Best practice guidelines for implementing family-centered care for children with disabilities in the North West Region of Cameroon

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**Guidelines Status** The first version of the guidelines was developed over 2009-2011, and reviewed and disseminated in 2012 and 2013. These guidelines can be added to and developed further based on interest, need and availability of persons to do so.

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## Scope

### **Objectives**

These guidelines provide recommendations about how the Ministry of Social Affairs, other ministries working with families, DPOs (disabled persons organizations), and community organizations can support families who have a child with a disability. The recommendations focus on improved home based care particularly psychosocial care and material care/basic needs; these guidelines also discuss the family support systems that are needed to help meet the other care needs. The guidelines are presented in a clear language format, as simple as possible so that they can be easily used and understood by parents. They may also be used by medical and health personnel.

### **Health Care Settings**

The guideline is targeted to community and home-based settings.

### **Target Population**

Children below 18 years who have physical, mental, visual and/or auditory impairments.

### **Intended Users**

Parents, guardians and relatives of children with disabilities (CWDs) shall use these recommended practices. Community groups, churches, rehabilitation service providers, government agencies, community leaders, and traditional leaders can implement and disseminate the guidelines.

## **The Current Situation for Parents and Families**

In the North West Region, many parents of children with disabilities and family members still have myths and misunderstandings about disabilities. They are often not well informed, and are ignorant about disability issues and raising up a child with a disability. Our group believes that there is urgent need for a change of attitudes.

At the same time, many children with disabilities are the focus of the African family. Their well-being and future are therefore of great concern to families and their communities. The majority of parents and families have very poor backgrounds characterized by low incomes, high prevalence of diseases, and inadequate nutrition. These factors increase the incidence of impairments and disabilities, which are further aggravated by the lack of suitable facilities, the inaccessibility of roads to reach support and treatment services, and generally poor infrastructure (e.g., phones and internet services are not readily available).

At present, there are thousands of children living with disabilities in the region. Many of them are not in school. Some parents do emphasize the need for their children to attend school, and search out schools that have adequate and appropriate support and access. There are very few support groups for parent of children with disabilities, and few sources of information.

## What We Did

**Method used to collect evidence:** Evidence was collected using a search of the following electronic databases:

- Google Scholar (<http://scholar.google.co.uk/>)
- The CIRRIE database of International Rehabilitation Research (<http://cirrie.buffalo.edu/search/index.php>)
- National Guideline Clearing House (<http://www.guidelines.gov>)
- Guidelines International Network (<http://www.g-i-n.net>)
- Scottish Intercollegiate Guidelines Network New Zealand Guidelines Group (<http://www.nzgg.org.nz>)

Search words included: family, care, Africa, Cameroon, children with disabilities and self-esteem. During the search, we did not identify existing best practices on family-centered care for children with disabilities in a developing country context. Therefore, there were no core reference guidelines to use to validate/compare to our current practices. As such, the best practices guideline adapted a variety of different pieces of evidence to compose the contents of this document.

**Method used to select evidence:** To ensure that evidence selected and reviewed was related to the scope statement, a brief review of each abstract and discussion/conclusion was done to ensure content of the evidence related to psychosocial, material and basic needs, medico-sanitary care of children with disabilities, and support systems for parents and families. Another consideration for selection of appropriate evidence was to select articles relating to practice in Africa or similar contexts (e.g. Asia). Articles from developed countries were reviewed but not selected for developing these guidelines as recommendations often did not reflect the Cameroonian context. It is interesting to note that the majority of literature identified spoke about the support needed for parents of children with disabilities and the stress they experience, whereas, the scope of our context was to focus mainly on the care needed to be given to children with disabilities with an indirect focus on support needed for parents.

**Method used to assess the quality and strength of evidence:** Each piece of evidence was categorized according to the levels listed below. During the literature search, a variety of evidence with the highest strength was sought out, however, in reality, there seems to be a scarcity of rigorous literature (Level A or B) on family-centered practices globally and in the African context. Many of the articles deemed appropriate and included as part of these guidelines were classified in Levels C and D.

Level of evidence	Type of evidence
A	Strong recommendation. Evidence from randomized controlled trials or meta-analyses of randomized controlled trials. Desirable effects clearly outweigh undesirable effects, or vice versa.
B	Single randomized controlled trial or well-designed observational study with strong evidence; or well-designed cohort or case-control analytic study; or multiple time series or dramatic results of uncontrolled

	experiment.
C	At least one well-designed, non-experimental descriptive study (e.g., comparative studies, correlation studies, case studies) or expert committee reports, opinions and/or experience of respected authorities, including consensus from development and/or reviewer groups.
D	Expert opinion, formal consensus

**Method for formulating recommendations:** A comparison table was developed using the format below to help determine appropriate recommendations to make. The idea of this table was to compare current practices identified in the North West Region as per the scope statement (i.e., psychosocial care, material care and basic needs, medico-sanitary care, support systems to parents) to recommendations made in the literature on those areas, while ensuring that levels of evidence of articles for each recommendation are noted and considered.

### Comparison Table

Current Practices in Family-centered Care for Children with Disabilities	Recommendations from Evidence	Author and Level of Evidence
1. Psychosocial care		
2. Material care and basic needs		
3. Medico-sanitary care		
4. Support systems to parents		

From the findings of this table a discussion arose within each of the 4 areas of the scope statement. Recommendations were discussed in terms of feasibility within the local context within the short and long term, considering the existing and potential resources at hand and possibilities appropriate to the context. Based on this the first draft of the guidelines was developed.

**Method of guideline validation:** The first draft of the guidelines underwent a further two-step process of validation, expert and practitioner review.

1. **Expert Review:** Members of the group who developed these guidelines were experienced practitioners and leaders in the field of family-centered care of children with disabilities in the North West Region of Cameroon. To further validate the recommendations formulated by these persons, 3 experts were identified who could further validate and confirm appropriateness of recommendations made. Experts were deemed person who had worked in the field of family-centered care (or with children with disabilities and their families) for at least a 5 year period, preferably who had produced written work (published and unpublished) in the area, who had possible presented on the topic of family-centered care at local conferences/seminars, and lastly who had received some type of education/formal learning in the area to substantiate their knowledge base.

Feedback of experts was incorporated to improve the content of these guidelines to produce a second draft.

2. **Practitioner review:** To ensure the format used to present these guidelines is user friendly, a small group of practitioners in the area of family-centered care (e.g., CUAPWD, MINAS, SENTTI) were shown the first draft of these guidelines and asked for their input on how relevant, understandable and feasible these guidelines could be in their work. Recommendations were noted and included in the third draft.

## Recommendations

The recommendations fall into three areas. The three areas are not discrete, there are connections and overlaps between them areas.

Recommendations 1 – 14 focus on **psychosocial care**, especially for parents and caregivers.

Recommendations 15 – 21 focus on **basic needs, material and educational care**.

Recommendations 22 – 31 are particularly relevant to **programs, organizations** and others who are working to support parents.

**Please note that these guidelines will be rewritten to be in a clearer language, graphic format or video story in the next stage of the project, so that they can be more easily understood by families and front-line providers.**

**After each of the recommendations, there are examples to help make these recommendations clearer to the user.**

**Example 1:** Ngwa Elizabeth and Suh Tom are parents to four children. One is a little girl, Mary, 7 years old, who has a mobility impairment. They live in Bamenda.

**Example 2:** Ndi Eric is a boy of 12 years who has a severe visual impairment. He lives in a small village with his extended family. His father died when he was young, and his mother works in another city and does not have much money.

### Recommendations about Psychosocial Care

1. **Quality interaction with a parents and friend is one of the most important factors** for healthy child development and creating success later on in life. [Tirussew 1999, Level C]
2. Children who come from one parent or two parent households both succeed, what is **most important is that the child has good parental interaction with at least one adult** – which could also be a grandparent or an aunt/uncle. [Tirussew 1999, Level C]
3. **There are 4 components to quality interactions that created good psychosocial support**, they are mutual understanding, love, acceptance and tolerance, and the child with disability being able to share responsibility within the family. [Tirussew 1999, Level C]

Family members, especially mama and papa, should always converse, tell stories, discuss issues and play with their children with disabilities. Show your children that you love them and accept their condition by what you say or do.

Give them the kind of housework they can do and only help or assist them when they ask you to do so. When you always converse, accept and love your child with a disability, so too the child will learn to be sociable, loving and accept his/her disability.

A child with disability who grows up even with the grandparents, relatives or friends also needs their love, acceptance, understanding and good social relationships. Parents and relatives should learn to accommodate any naughtiness, destructive tendencies or temper tantrums as a result of the child's disability. They should also exercise patience towards the child with disability.

- **Example:** Elizabeth and Tom spend time with Mary, playing, talking about school, and helping her to take part in the chores and activities in the household. They often tell her that she is loved, just like they tell their other children. As much as possible they treat her like their other children.
- **Example:** Ndi does not often see his parents because they don't live in the village, but his grandparents, aunts, uncles and others in the compound make sure that he is included in all family activities and that he attends school. When he wants to go to his friend's house to play, they take him and encourage him to enjoy the time with his friends.

4. **The strengthening of relationships with a child should be the focus of child development programs** and parents should take advantage of such programs when possible. [Richter 2004, Level D]

Parents of CWD should learn to build a strong relationship with their child. You can do this by spending time with him or her, seeking advice from the social welfare service, pastors/priests, Disabled People's Organizations or attend such seminars or training whenever they are organized. Also attend antenatal lectures (clinic talks) regularly. Parents should also form Associations of Parents of CWDs for mutual support and advocacy.

- **Example:** A few times a month, Ngwa is able to participate in a community program for parents in her neighbourhood. There she is encouraged to try different activities with Mary so that she gets to know her better, and that they can have fun together.
- **Example:** Ndi's aunt worked with others in the village and with a large NGO to develop a program where families could learn about child development and how they could support the growth of their children. His aunt advocated to making sure that children with all kinds of disabilities would be included in the program.

5. **Children who interact with people outside their family (e.g., neighbors, hospital staff, teachers) have good development.** [Sloper et al 2007, Level C]

Children with disabilities like to travel and know places, things, and people just like other children. Your child with disability will grow well and know many things if you often take him or her out on excursions, on strolls, to youth camps, social gatherings, cultural festivals, sports competitions, church, and market places. Take him or her out to meet

friends, relatives, and colleagues. Do not hide your CWD in the room or at home out of shame. Your child can achieve a lot in life.

- **Example:** Mary's parents and other family members don't talk on her behalf when they are out. They allow Mary to speak for herself, and only intervene if necessary. Sometimes, people are surprised and don't want to talk to Mary herself, but her parents insist (gently) that they don't talk for her and that she is very able to speak for herself.
- **Example:** With his family's support, Ndi has learned to move around the village and people have gradually learned to talk with him like any other child. He goes to the market when his grandmother needs something, and is able to buy from the vendors. Neighbours always greet him as they pass by.

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| <p>6. <b>Early childhood educational experience is important</b> for cognitive, sensory and communicative stimulation as well as social competencies, which are needed for learning. [Tirussew 1999, Level C]</p> <p>7. <b>Children's play results in learning.</b> They have the opportunity to express themselves, assume different roles and interact with their peers. Children need to relieve stress and tension through play and outdoor activities provide this opportunity. [Morrison G.S 1998, Level C]</p> |
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Teach your child how to speak and communicate well especially through story telling or do mental calculations or reason things out. Your child should make and interact with friends, and to play and learn with them. Prepare your CWD for school right from birth by gradually and regularly training him or her how to talk or communicate well, reason and take decisions, do simple calculations or mental work, and play educative games like puzzles, scrabble, monopoly, cards or draughts. These games may need to be adapted for the CWD to take part and enjoy them.

Parents should also make assorted toys available for exploration and play. Parents should make the home secure, safe, and stimulating. You should provide opportunities for CWD to explore the environment, to question, to play, to experiment and to symbolize (use symbol and signs). Parents should invest educationally in the CWD, because whatever is invested in childhood pays a lot for the success and achievement of the person in adult life.

- **Example:** Mbakwa has been attending school since she was 3 years old. Her parents spend time with the teachers to ensure that they understand her impairment, and how to assist her when necessary. They helped the school to install an accessible toilet so that she can be comfortable and independent.
- **Example:** Because he lives in the village there were few opportunities for Ndi to have early education that could accommodate his visual impairment. However, his family did all they could from the time he was young to read to him and to encourage him to learn. He attended a special school for two years where he learned to read and write Braille.

8. **Children with disabilities who succeed most in life had learned to use good coping strategies in the face of common difficulties**, such as: ridiculing by teachers and non-disabled student, inaccessible schools, and lack of special education materials. [Tirussew 1999, Level C]
9. **During times of big difficulty, children who succeed had someone to talk to, such as a family member or a friend.** [Tirussew 1999, Level C]

Parents can trust and believe in the mental, physical, and character abilities of their CWD. Children can do many things when their communities and their parents believe in and get to know their potentials. They will also believe in themselves and so be more able to ignore all forms of ridicule or social stigma.

Provide your child with his/her basic special needs like white-cane, wheelchair, glasses, hearing aids, or with special education needs like communication skills, Braille/sign language, Braille machines and papers.

If you really trust and believe in your CWD, she or he will always tend to confide in you in times of stress, difficulty, frustrations or worries. Children who have people or someone to support or back them up often succeed highly in life.

- **Example:** Lum's mother and elder sister always take time to listen to Lum's experiences. They know that she needs someone to lean on sometimes. Every day when she comes home from school, her mother asks her how the day was and she listens carefully to what Lum says. Lum has learned several ways to cope with difficulties because of these conversations. She has also learned that she can come to her mother and sister if she has a difficult experience and they will help her to figure out how to cope with it.
- **Example:** Ndi has an elderly uncle who also has a disability. This uncle tells Ndi about his own experiences, and helps Ndi to solve problems whenever he is feeling discouraged or alone. When Ndi came back to the village from his two years away learning Braille, it was his uncle who went with him to the school to make sure that the teachers would accept him back. His uncle is always reminding Ndi that no matter what, he will be there to talk with him.

10. **Children who succeed have personal strengths** such as: accepting their disability, being tolerant, working hard to learn, showing their potential through creative ways, trying to be accepted by others, creating close relationships with other children, and good time management. [Tirussew 1999, Level C]

CWD who have developed high confidence in themselves will be determined to overcome all obstacles on their way to success in life. They will learn to work hard, ignore criticisms and stigmatization, be perseverant and tolerate all persecutions. CWD with high self-esteem are cheerful and make friends more easily. They develop self-control and learn how to use their time constructively/well. A child develops self-confidence when parents appreciate what the child does, allows the child to do things for himself/herself with guidance.

Parents can assign responsibilities and believe and focus on the child's abilities.

- **Example:** Shen and Apong and others in their family work hard to help Mary learn how to develop her own personal skills and strengths. When Mary showed some aptitude in singing, they helped her to join the church choir and to sing more at church. Together the family helps Mary to develop strategies for moving around the city.
- **Example:** Because Ndi has been left on his own at some times, he developed several skills and strengths, such as understanding how he could learn in a regular classroom by talking with his teachers and classmates to set up strategies that include him in classroom activities.

11. **A child will develop self-esteem when he or she is able to achieve things,** so the child should have many opportunities to try things and learn to improve at them and achieve small goals. [Tirussew 1999, Level C]
12. **Parents should clearly celebrate achievements of children,** at the same time if a child is not progressing regularly, maintaining a child's function should be the goal and the child encouraged on this as well. [Sloper et al 2007, Level C]
13. **A child's self-esteem also strongly depends on how he or she thinks a parent or teacher sees him or her.** If a child feels a parent/teacher believes in his/her abilities, and has a good opinion of the child, he/she will have more self-esteem; if the child feels undervalued by parent, their self esteem will be low. [Tirussew 1999, Level C]

Allow your child to try things out for himself or herself, because they will be proud of themselves when they succeed. If he or she does not succeed, encourage them to try again. Rejoice and celebrate with the child each time he or she achieves something important. This enables the child to build more self-confidence and a feeling of greater achievement. If you believe in your child's abilities, the child will equally believe in his/her own ability to achieve.

- **Example:** Bih's family has a tradition of celebrating all of the children's achievements at the end of each week. Each child, including Bih, reports on what they have accomplished during the week, and they especially celebrate failures that have been turned into successes. One week, Bih talked about how she did not know how to play a particular game with the other girls during the lunch period but then she was able to see that she could take a role in the game and the other girls accepted her participation.
- **Example:** Ndi's grandparents, parents and other extended family members are always giving him work to do, just as they would give other children in the house. They insist that he tries, and they help him if it is difficult. Only after several attempts do they give up if he is not able to do something. From this approach, Ndi has learned to shell egusi, to do laundry, to wash dishes, to sweep floors, and many other household tasks.

14. **Poverty is one of the key difficulties to overcome, so parents can show love to their children.** Families living in poverty have more difficulty with showing love to a child with a disability as they are facing stress. [Park et al 2002, Level C]

Poverty in the family increases the worries, stress and therefore conflict or quarrels arise. Such a family may have to work harder to know peace and show love and affection to their children, especially CWD. Parents too should be versed with and seek assistance from the support services in the locality. Parents should continue to show love and affection to children even in times of poverty.

- **Example:** Mary's parents live with poverty but they are clear to all of their children that love has no price tag. Every night before sleeping, either the mother or the father or both of them tell all the children that they are loved.
- **Example:** Ndi's family doesn't have much in material goods, and they rarely say that they love him but from other things that are said and the way they behave, he knows that they have a strong love for him. They include him in family activities, they ask him to do things for them, and they talk about him proudly to others outside the family.

15. **It is important for all children to have friends** and going to school increases the chance of this, children get frustrated if they do not have any friends. [Sloper et al 2007, Level C]

Generally, children are friendly and want to make friends. Children with disabilities may not easily have friends because their condition might not have been understood by other children. As a parent, encourage other children to socialize with your CWD. Once they understand him or her, they will make good friends. Ask your child to name all his friends, discuss their qualities and guide the child.

- **Example:** Sirri has been going to school since she was three. Her parents have encouraged her to have friends from school, and often allow her to invite friends to come to the house, sometimes even sleeping over for the night. They also allow and encourage her to visit her friends from school and from the neighbourhood. They are clearly not ashamed of her.
- **Example:** Che's family does not have much money but they try to find the funds to allow Che to invite his good friend, who is blind, to visit during the school break.

#### **Recommendations about Material Care, Basic Needs, Education Needs**

16. **Children with disabilities who attend school between the age of 5 and 8 (similar to peers) are more likely to succeed** as adults compared to children who start school later than other students. [Tirussew 1999, Level C]

CWD have the right to go to school like other children and to start school at the ripe age of 5 years and have all his/her school needs provided. Such CWD are very likely to

succeed in life. Parents should try to save money for the child's school needs and enable the child to start school like other children.

- **Example:** Lum, who is disabled, started school at 7 years. She soon had many friends (peers) who studied together with her even back at home. Lum and her friends did very well in their final exams
- **Example:** Although Niboh was going to school from a young age, there have been times when her parents had to advocate for her to be accepted in the classes they wanted to place her in. Some of the teachers thought she was too young. Her parents talked with the teachers to inform them about how important early education is for her development.

17. **Children with disability who interact with children without disabilities learn to feel supported, accepted and a sense of belonging.** It is important to create opportunities for this child mixing and interaction. [Tirussew 1999, Level C]

18.

Parents of CWD should encourage their CWD through play and other outdoor activities so that they love and understand themselves and their differences.

- **Example:** Che is a CWD who loves to play with his friends. His friends often take him along during play time. Che will act as a referee and at other moments as coach or March delegate. His absence often creates a huge gap.

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19. **Being able to communicate is a basic need to help a child feel understood, socialize, be active in the community life and learn to be independent.** All children should have the opportunity to communicate in one way or the other, and others should be trained to learn to understand the child. [Sloper et al 2007, Level C]

Family members and relatives of children with disabilities should do everything possible to learn how to communicate with their children. For example, parents can learn sign language so they are able to communicate effectively with children who have hearing impairments. Be patient and tolerant when talking with a child who stutters or stammers and try to get a speech therapist to remedy the situation.

- **Example:** Ngong has hearing impairments and has learned sign language. His parents and other family members have also been trained in sign language too. Communication in the household is easier now.

20. **Children want to feel 'normal' and like everyone else, wearing clothes like other children is important.** [Sloper et al 2007, Level C]

Parents! Make sure you keep your CWD neat, clean and looking good. Dress him/her up as you would do to other children. When children look neat and attractive, they are loved and are more friendly and understanding.

- **Example:** The parents of Bih dress her daily like other children in the house. Bih likes it and has participated in proposing some style of dresses. This gives her a feeling of belonging and her self-esteem is high and she feels good in her beautiful and fashionable dress.

21. **Even when good medical and nutritional care is available, for very young children who do not have human contact and attachment to a caregiver, they may stay malnourished and even die.** Good human relationship as well as nutrition/medical care is the mixture needed. [Richter 2004, Level D]

“Health is wealth” and a fundamental right to every human being. Regularly watch the health of your child and let him/her have all the required health care needs like vaccinations and balanced nutrition. The CWD should not have the double problem of ill health and disability. Have a good relationship with your child, just as you have with any other children.

- **Example:** Tata lives with her aunt and other children in the household. They have adapted a table to suit Tata so that they can be eating and chatting together during meal times. Tata’s appetite has increased.
- **Example:** Ful is a child with a disability. His parents take him for consultation whenever he is not well, just as they would do with their other children in the family. When they meet with the doctor or the nurse, they take the time to inform them about his condition and how it affects his health. They do not tolerate any health care professional to speak disrespectfully to Ful.

22. **Psychosocial care and material care work together,** one should not exist without the other for healthy child development, material care is not enough. Maslow’s hierarchy is not recommended for the care of children in very difficult situations. [Richter 2004, Level D]

One cannot have concern and love for the CWD without trying to provide the child’s basic and special needs such as food, safety, clothing, education, health, white cane, wheelchair, crutches, hearing aids, tricycle etc. Papa and mama! Love your CWD, take good care of their health, safety and education and buy their assistive devices.

- **Example:** The regular visits that Lukong receives from his family members and discussions about his situation have improved his understanding of his disability and he no longer has so many worries. He is happy that he is being listened too and the myths and fears have been eliminated.

23. **Parents have a leading role in making sure their children are included by society and in educational settings.** [Bwana and Kyohere 2002, Level D]

Parents should give their CWD their own share in the housework, encourage them to participate in children's games within the neighborhood and in school, involve them in making decisions that affect or concern them and discuss the special needs of their CWD in church and "quarter-meetings", PTA meetings, "country-meetings", and community planning meetings.

- **Example:** Mabu's parents have made a duty to take their children to school and follow them up. School administration and other people in the society that watch them daily have changed their attitudes towards Mabu and other CWD as they admire the way the parents do care.

**Recommendations especially for Program Developers, Schools, Organizations:  
Support systems for parents of children with disabilities**

24. **Most parents want their children to achieve at least basic reading, writing and numbers skills.** It is important to support parents to do this even if it involves home schooling. [Sloper et al 2007, Level C]

Parents should immediately contact any social welfare service or the municipal authority in the locality once impairment (disability) has been discovered in a child. Invite a special education teacher or a community-based rehabilitation worker or any other specialist who works with CWD to assist you in preparing the child to start school and in advising you on how to care for the child. The social welfare service, health care providers, school authorities and religious organizations in the locality should form a network of actions in favour of CWD and their families.

- **Example:** Musa's mother is a teacher. She has prepared a learning place at home, and equipped it for Musa. Every day she assists Musa with basic learning skills. She encourages Musa to do drawings/sketches, simple calculations and writing exercises.

25. **Poverty is the biggest challenge for parents and this affects the children as their parents cannot give the love and care they need. Parents should be supported to overcome poverty so they can give better care to their children.** Poverty affects family interactions, health access, ability of children to learn/develop thinking skills, healthy emotional development and a healthy home environment. [Park et al 2002, Level C]

Parents of CWD! Come together and form "support groups" (e.g., form Association of Parents of CWDs) or join any other vibrant group in your locality that shares the concerns of PWD so that the group can be assisted in carrying out income generation activities to improve the income levels of its members.

- **Example:** The parents of Ann belong to a farmer support group that supports inclusive societies and recognizes the needs of people with disabilities. They were

able to receive improved seeds and other farm inputs through this group and this has improved their yields. Advocacy through their group is more effective, and that is why government and other NGO have promised to come in next year to assist again.

26. **Families of children with disabilities are hit harder by poverty than any other group, including families of non-disabled children or affluent families of children with disabilities.** They should be the first target of social programs and poverty alleviation initiatives. [Park et al 2002, Level C]

Local economic operators, development organizations, finance/credit institutions and the municipal council should organize outreach/income generation, poverty alleviation programs for groups and families of CWD in their locality. The municipal council as well as the local social services should regularly organize educative, sensitization as well as counseling programs in favour of CWD and their families.

- **Example:** Ndang's mother spends most of her time attending to Ndang because of her disability. She is mostly involved in activities like taking her for physiotherapy and other treatments. She needs finances for wheelchair and to pay consultation fee. She is able to access a program offered by her municipal council to learn more about what services are available in her community.
- **Example:** A town's municipal council decided that every program they administer will be looked at to include persons and families with disabilities. This does not mean that families of CWD are given preferential treatment, just that they are specifically included. When providing a new program or service, such as a road or water service, the councilors ask themselves questions such as "How will a poor family of a child with a disability be able to participate in this program? Do we need to take any additional action to ensure that they can participate?"

27. **Programs that promote the income of families also show promotion of the cognitive development of children.** To improve the life of a child, the whole family needs must be addressed, not only the child. [Park et al 2002, Level C]

People or organizations working with CWD and their families should not only address the personal needs of the CWD but should also care for the collective needs of the child's family especially psychosocial, education/communication, health and material needs.

- **Example:** A local organisation provided a grinding mill to Ngu's family to support them economically so that they can care for Ngu, who was disabled and living with a mobility impairment for most of her 17 years. In addition, the organisation provided psychosocial counseling to the family to strengthen family relationship and ties. The family now lives in harmony and Ngu's disability is no longer a worry.

28. **Government and social institutions (e.g., orphanages) cannot substitute for the role of a parent.** Each child needs at least one caregiver who is devoted to the current and future well-being of the child. The child needs a stable relationship with one caregiver. [Richter 2004, Level D]

Parents of CWD should endeavour to have someone in the home (caregiver) who will be personally responsible for taking good care of the CWD. Let orphanages or child care institutions be only temporary places for formation if they must be homes for CWD. These places cannot provide the family warmth, care and love that the child needs.

- **Example:** When his mother died, Henry was taken to an orphanage with all the facilities and in the hands of devoted staff but he refused food and play and cried throughout because he missed the warmth of his family members. The orphanage looked for a way to provide support to Henry's extended family so he could return to live with them.

29. **Caregivers must be given the support they need to care for a child, this is the key role of government and service organizations.** Organizations can sensitize parents on the cognitive and emotional needs of a child and simple ways the parent can meet these needs in the early years. [Richter 2004, Level D]

Caregivers are very important persons in the home. Their services should not be underrated. They can cause a disaster as well as they can give very good care to the CWD. They should be highly appreciated, encouraged, and supported so that they do their work cheerfully.

Community organizations and services should educate and sensitize parents of CWD on the child's disability as well as on the resultant emotional, learning, and special needs. This includes quality interaction, self-help or daily living skills, accessibility to environment and assistive devices.

- **Example:** The capacity building workshop that was organised by the social center has enabled Ma Jane to gain new skills in psychosocial support, and understanding of the cognitive and emotional needs of her child. Ma Jane is gradually inserting these new skills in her daily interactions with her child.

30. **Parents must also be supported to include their children in all aspects of society,** such as family activities, community activities, schools, religious groups, etc. [Richter 2004, Level D]

Community leaders such as administrative, religious, traditional, political and civil society authorities should conceive educative, capacity-building and developmental programs that take into consideration the rights and duties of PWDs in the family, the neighbourhood and the community.

- **Example:** The Parents of Sam, a CWD, is often visited by the school authorities, the Pastor and other community members. This has encouraged them to always take their child to church, school and community activities.

31. **Mothers of children with disabilities are said to experience ‘apathy-futility’ syndrome (apathy = lack interest, enthusiasm, concern; futility = pointless) and therefore they need support to feel different and see the situation differently if they are to behave differently. [Richter 2004, Level D]**

Successful PWDs and parents of CWDs should be invited to local sensitization programs to participate as role models to families of CWD. Employers, families of PWDs and PWDs themselves should be sensitized on the career opportunities available for PWDs. Attitude change media and community oriented campaigns should be carried out by community leaders.

- **Example:** The regular contact visits, counseling and family support that Ma Ngum receives from social workers, community organizations, and community members gives her great relief and now she is going about her activities normally. She was able to talk with them about her feelings that it was pointless to do anything for her child. Gradually her feelings changed, and she could see that it was not pointless. She now looks at her child’s disability as a blessing.

32. **Caregivers need to be supported to have a positive mental state and good motivation if they are to respond to the needs of their young children. [Richter 2004, Level D]**

Parents, house helps, and caregivers for CWD need also to be loved and cared for so that they can in turn express love and care for their CWD. Correct and instruct them politely; provide for their needs; assist them in their care giving; and always thank them for, or appreciate their work.

- **Example:** Family relations of Ma Prisca are always around her, appreciating her and reassuring her. Some people offer to take care of her child, and they do so loving care so that she can have a break from her care giving responsibilities. She feels happy with this and this has improved her mental state as she feels that others care for about her and her CWD.

33. **Parents associations are good to help support families and create productive networks. [Bwana and Kyohere 2002, Level D]**

34. **Parents should form associations and act as advocates for their children with disabilities. [Obi F.B (2004) in Effective Parenting of Children with special needs, Level D]**

Parents of CWD should join parents’ associations or support groups so they can support one another, attract the assistance of development organizations, and be a source for social connections that would be productive.

- **Example:** Pa Mathew joined an association of Parents of CWD. The experiences of members shared during meetings has enriched his skills in caring for his CWD. He had the opportunity to share some difficulties and received proposals and how to handle them.

### **Evidence Supporting the Recommendations:**

1. Sloper, P., Rabiee, P., Beresford, B. (2007) Outcomes for Disabled Children, Research Works, The University of York, n.2007-02. [**Sloper et al 2007, Level C**]
2. Park, T., Turnbull III, (2002). Impacts of Poverty on Quality of Life in Families of Children With Disabilities, *Exceptional Children*, 68(2): 151-170. [**Park et al 2002, Level C**]
3. Tirussew, T. (1999) Retrospective study of childhood experiences of persons with disabilities and high achievement profiles in Ethiopia. *Ethiopian Journal of Health Development*, 13 (3), 195-204. [**Tirussew 1999, Level C**]
4. Richter, L. (2004) Early Child development in resource-poor settings: Balancing children's material and mental needs – a personal account, *Zero to Three*, November issue. Accessed on-line April 24, 2011  
[http://74.125.155.132/scholar?q=cache:2IMnGs3bBzkJ:scholar.google.com/&hl=en&as\\_sdt=0,5](http://74.125.155.132/scholar?q=cache:2IMnGs3bBzkJ:scholar.google.com/&hl=en&as_sdt=0,5) [**Richter 2004, Level D**]
5. Bwana, O. & Kyohere, O. (2002) Parents' Role in CBR. CBR: a participatory strategy in Africa. The centre for international child health. Accessed on-line April 24, 2011 at <http://www.asksource.info/cbr-book/cbr09.pdf> [**Bwana and Kyohere 2002, Level D**]
6. Obi, F.B (2004): *Effective Parenting of children with special needs: a book for parents, special educators, counselors and related professionals*
7. Morrison, G.S (1998) *Early childhood education Today*. 7<sup>th</sup> edition Merrill Prentice, New Jersey

### **Background documents**

**United Nations. (2006). Convention on the rights of persons with disabilities** and optional protocol. Geneva: Author. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>  
All of the convention is important. Article 7 specifically talks about children with disabilities, Article 23 talks about family and home life.

**United Nations (1990) Convention on the Rights of the Child.** Retrieved from <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx> Article 23 recognizes the rights of children with disabilities.

**Cameroon Law N0. 2010/002 of 13 April, 2010** relating to the protection and welfare of person with disabilities. All of this law is important for children with disabilities and their families. Focuses inter alia on access to education and vocational training, information and participation in cultural activities, housing, leisure activities.

## Implementation of the Guideline

### **Benefits of implementing the guideline**

These guidelines aim to develop quality practices within the North West Region in family-centered care for children with disabilities across different contexts (e.g., rural and urban areas, families of all income levels). The benefits of following these guidelines are that practitioners and institutions will improve their support to parents and families of children with disabilities, which will in turn create stronger and confident adults with disabilities.

### **Strategies and recommendations for Implementation**

The best practice guidelines developed in this document are expected to be utilised by stakeholders in disability and rehabilitation issues. We know that parents particularly need support and information. However many parents and caregivers will not be able to read these guidelines, so we also have in mind people who can help families - persons with disabilities themselves and their families, social workers, rehabilitation and health workers including Community Based Rehabilitation (CBR) workers, related governmental professionals, civil society and Municipal authorities as well as traditional rulers.

We recommend that the next steps for this work include implementation, monitoring and evaluation.

The implementation plan shall comprise:

- a) Identification and needs assessment of CWD – there is relatively little information about children with disabilities in our region.
- b) Education and sensitization of all stakeholders.
- c) Provision of direct support to CWD and their families.
- d) Follow up and monitoring of best practice guidelines (BPG) implementation. We would like to know how these guidelines have been used and what impact they have had.

Identification and need assessment of CWD needs to be vigorously carried out by professionals, practitioners, civil society organizations (CSO) working with disability issues in the various communities.

Education and sensitization programs could comprise the organization of media talks and conferences, seminars, workshops, symposia and focus group discussions (FGD) with each category of stakeholders and the beneficiaries in all the seven Administrative Divisions in the North West Region.

Most importantly, as stated above, developing materials such as popular films or simple storybooks, that would be accessible and understandable to parents and caregivers, is very important.

The education and sensitization program could be expected to empower stakeholders on how to use the best practice guideline and its recommendations as well as to overcome the challenges involved in their implementation.

Ideally, provision of direct support to CWD and their families using a vulnerability scaling could be provided to the most needy.

Monitoring and evaluation of the implementation plan should comprise regular follow up of parents and families of CWD as well as community leaders and organizations in their respective roles in implementing the guidelines. Regular follow up and evaluation could be ensured through professionals and practitioners in the communities such as health, rehabilitation, and social workers, head teachers, municipal councilors, and civil society activists working together.