

New Paradigm of Medical care for Persons with Disability
A Multi-Country Action Research Joint Initiative of WHO/DAR & AIFO/Italy
Mid-Initiative Verification Meeting
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PRESENTATION COLOMBIA

The Colombian project is situated in Piedecuesta, a town with the population of 120,000 in the state of Santander in Colombia. Piedecuesta is a colonial town with a central square and park bordered by the principal cathedral, the municipal buildings and shops. The streets in the old part of the city are quite narrow with houses bordering on narrow sidewalks. Recently the sidewalks in the city centre have been widened and made wheelchair accessible, which is a promising indicator of awareness regarding disability issues.

ASODISPIE, or disabled people of Piedecuesta, is the local manager of the project. ASODISPIE is a disabled people's organization that was founded and registered as a charity in 1997. The organization was established in response to the poor level of services and support for disabled people in this area. ASODISPIE has approximately 180 members and rents a building in the older section of Piedecuesta.

Our project has four focus groups: spinal cord injury (SCI), spina bifida (SB), Downs syndrome (DS) and cerebral palsy (CP). The SCI group is composed mainly of adults, but parents and children make up the majority of the remaining groups. Typically, each group meets separately once a month and with the other groups once a month. Meeting in separate groups helps the participants to gain comfort with expressing their thoughts and sharing their experiences in a peer group. Joint meetings between all the groups helps create awareness about the diversity of disabilities, to establish relationship with the broader community and to talk about issues common to all.

Attendance in Year 1

In the first year we had 45 meetings with a total attendance of 490 as demonstrated by the table below:

Table 1.

February to December 2006

| Month | DS (9) | SB (7) | CP (22) | SCI(12) | Combined (52) | Total attendance |
|-------|--------|--------|---------|---------|---------------|------------------|
| FEB | 3 | 5 | 11 | 7 | | |
| MARCH | 5 | 5 | 21 | 12 | | |
| | 6 | 5 | 16 | 10 | | |
| APRIL | 4 | 5 | 17 | 8 | 20 | |
| MAY | 5 | 4 | 13 | 8 | 20 | |
| JUNE | 7 | 6 | 13 | 8 | 20 | |
| JULY | 7 | - | 14 | 8 | 31 | |
| AUG | 4 | 2 | 14 | 5 | | |
| SEPT | 4 | 3 | 8 | 5 | 38 | |
| OCT | | | | | | |
| NOV | 5 | 5 | 13 | 9 | | |
| DEC | | | | | 51 | |
| TOTAL | 50 | 40 | 140 | 80 | 180 | 490 |

Attendance in Year 2

In the second year we had XX meetings with a total attendance of XX as shown in Table 2.

Table 2.

February to December 2007

| Month | DS (9) | SB (7) | CP (22) | SCI(12) | Combined | Total Attendance |
|-------|--------|--------|---------|---------|-----------------------------|------------------|
| FEB | 6 | 5 | 14 | | 14 | |
| MAR | 5 | 6 | 13 | 5 | 30 | |
| APR | 6 | | 12 | | | |
| MAY | 2 | 3 | 6 | 6 | 23 | |
| JUNE | 4 | | 11 | | | |
| JULY | 2 | 4 | 6 | 4 | 10 | |
| | | | | | 27 | |
| AUG | 6 | 2 | 10 | 7 | 25 | |
| SEPT | 6 | 4 | 10 | 6 | 29 | |
| OCT | 6 | 3 | | 4 | Disability Day Halloween | |
| NOV | 5 | 3 | 14 | 7 | 29 | |
| TOTAL | 48 | 30 | 96 | 39 | 187 | 400 |

Identification of Needs

The emphasis in the first year was group formation and the development of a list of topics for which the participants in each focus group wanted further information and training (please see Appendix 1). From this response, we developed an initial strategy of topics to be covered for each focus group, a time estimate to cover these topics and the resources available in Spanish. We also developed a schedule to cover all of these topics within one year.

In mid 2007 it became apparent that the schedule that was made in 2006 was not working and that a new strategy for training with a slower pace and the repetition of topics needed to be developed. The topics from the schedule were compressed into main action categories (please see Table 3) each with its indicator by which to evaluate progress.

Table 3.

Strategic Action Categories

| PRIMARY PREVENTION | PREVENTION OF SECONDARY PROBLEMS | FAMILY & COMMUNITY |
|---|--|---|
| Adequate Stimulation (Children) | Chronic Problems | Community Rehabilitation |
| Gross and fine motor abilities Sensory abilities Cognitive abilities Social/communication abilities Personal independence <ul style="list-style-type: none"> • Conceptual abilities • Social abilities • Practical abilities | Respiratory problems Prevention and treatment of skin breakdown Urinary infections Constipation Scoliosis Malnutrition Other | Work Orientation & formation Human rights Inclusion Disability group strengthening Integration of the family in CBR Strengthening of family networks Disability pensions Other |
| Holistic Rehabilitation | Social & Psychological Risk | |
| Functional training Accompaniment Psychological & social | Neurosis Schizophrenia Bipolar disorder Difficulty in adaptation Other | |
| Healthy Nutritional Habits | | |
| Food classification Practice in preparing nutritious food Eating healthy food | | |

Capacity Building sessions

Training topics in the first and second year were drawn from the list of needs as developed by the focus groups. The project facilitators met with the professionals before the sessions to provide guidelines in regards to the topic and the teaching method desired. The sessions were given to the individual focus groups in most cases; sometimes focus groups were combined as in the case of SCI and SB for urinary tract infection (UTI) and pressure sore, and all the groups were combined for topics of interest to all such as Colombian Health Law. The materials used were “Disabled Village Children” by David Werner and material on the CAPD web site. A notebook was provided to each participant to write notes during the session, to document home exercises and to keep track of their own progress or journey. Some have been faithful in using the notebooks, but others have not perhaps due to lack of experience with keeping written notes.

In the first year, most of the training sessions were given by the project facilitators and covered topics such as:

- Needs and necessities
- Empowerment
- Characteristics of SB, DS, CP and SCI
- Characteristics of leadership
- Disability awareness and attitudes prevalent in society
- Specific needs, information sources, self care initiatives
- Plan of action
- Disability law
- Satisfaction survey

The majority of the workshops in the second year were given by professionals. Topics were drawn from the following categories in Table 3: Adequate Stimulation (Children); Holistic Rehabilitation; Healthy Nutritional Habits and Chronic Problems. Topics remaining to be covered fall under the categories Social & Psychological Risk and Rehabilitation based in the Community (CBR).

Special emphasis was placed on:

- Information on specific disabilities
- Urinary tract infection (UTI)
- Stimulation of gross motor & fine motor skills
- Communication
- Nutrition
- Epilepsy
- Functional training
- Colombian health law

Instead of rushing through the sessions in an attempt to cover everything, the facilitators chose to repeat some sessions. It was felt that new habits of self care could be formed through practice. It was not anticipated, however, that the participants would require several practice sessions on the same topic. It appeared that because some of the self care procedures being taught were a deviation from what the participants were practicing in the home, it took one session to create awareness and another one or two sessions for the participants to overcome their resistance to implementing new procedures at home. The process of achieving compliance is still underway.

Specific topics that remain to be covered for next year are found in Table 4.

Table 4

| FOCUS GROUP | CATEGORY | TOPIC |
|--------------------|----------------------------------|---|
| SCI SB | Prevention of secondary problems | <ul style="list-style-type: none"> • Treatment of pressure sores • Constipation • Posture • Stretching |
| | Family & Community | <ul style="list-style-type: none"> • Rights re labour & education • Sexuality • Family relationships • Self image |
| SB | Prevention of secondary problems | <ul style="list-style-type: none"> • Respiratory problems |
| SB | Family & Community | <ul style="list-style-type: none"> • Independence • Social development • Physiological & emotional issues |
| CP | Prevention of secondary problems | <ul style="list-style-type: none"> • Postural control |
| CP | Family & Community | <ul style="list-style-type: none"> • Independence in ADL * |

| | | |
|------|----------------------------------|---|
| | | <ul style="list-style-type: none"> • Behavioural conduct • Social development • Sexuality |
| Down | Prevention of secondary problems | <ul style="list-style-type: none"> • Hygiene |
| Down | Family & Community | <ul style="list-style-type: none"> • Behavioural conduct • Learning • Sexuality • Independence in ADL • Rights |

* ADL = Activities of Daily Living

FOCUS GROUPS

Leadership

Leadership within the groups developed over time. Of the four focus groups the SCI group has provided the most leadership within the project and some individuals have been willing to share their knowledge and experience with others. Leadership within the other three groups has been slower to develop because they were largely composed of family members who were not well integrated into the Association. Participation in the project has been helpful in this regard and many participants have developed a sense of belonging and acceptance within ASODISPIE. Leaders in all the groups have now been identified and some training sessions have been given although more work needs to be done in terms of determining their specific role and providing the necessary training for them to develop the skills required. The aim is to develop leaders who motivate attendance at meetings and carry-through in self care. To date, the leaders have gained confidence in speaking with the professional trainers and have encouraged other group members to do the same. They have also generated more trust within the group.

Participation

There has been a gradual shift in the participation of group members. Whereas they previously kept their thoughts private, they now express them openly within their groups. It took time to develop open expression because they were not accustomed to talking candidly about their issues with non-family members.

The groups vary in their sense of confidence to speak up or to participate in activities such as role playing. The SCI and SB groups have been most candid and talk openly about their attitudes towards self care and their habits in the home. They have gained the confidence to engage in

functional retraining activities in front of others. The CP and DS groups are also participating better as demonstrated by their willingness to do exercises with their children and to express their emotions, doubts and fears.

Communication with Professionals

Gaining experience in self expression with their peers in the first year helped them gain the confidence needed to relate to the professionals in the second year. Participation and communication with professional trainers was also enhanced by practice within the sessions. Practice provided a venue to ask questions and to clarify issues as well as to voice doubts and fears.

Changes in Self Care

Each group has its own characteristics in terms of pre-existing knowledge, acceptance of new information and motivation to change self care habits. In the past, for example, members of the SCI group had developed habits of urinary care based on home remedies and when they had an infection, they would wait until it was very serious before seeking medical assistance. They did not like to do catheterization or to go the health clinic because of bad experiences in the past. Thus they were fairly resistant to the training sessions on urinary care given by the nurse. By the end of the third session on the topic, resistance had reduced and they began to practice intermittent catheterization although not with the frequency suggested. These individuals are reporting an improved level of health due to reduced infection rate. By way of contrast, the mothers in the SB group were much more open to the teaching on urinary care practices and implemented it with less resistance.

The participants in the CP and DS groups have also had to deal with pre-existing attitudes before making changes in self care. In the past, many parents believed that their role was to make sure that their disabled child was clothed, fed and kept safe from danger – but no more. They didn't believe that their child had potential to learn or that they could be instrumental in stimulating his/her development. Parents of children with less severe disability have found it easier to make the adjustment in thinking but interest in learning about disability has also been noted in the parents of children with severe CP.

Change in Self Care Behavior

Although not all of the training sessions have been given to date, it is evident that skills are being developed in self care. In the past, self care is something that neither the disabled participants nor the professionals thought much about. At the end of the second year awareness regarding self care has developed in most and the participants demonstrate a desire to learn more.

A participatory evaluation held in November 2007 found that participants experienced some change as a result of the project. They highlighted changes in the physical, physiological and social spheres. These comments were placed according to these categories in Table 5.

TABLE 5

| SELF CARE | |
|---|---|
| PHYSICAL IMPROVEMENTS | |
| Improved Health | <ul style="list-style-type: none"> • I have fewer infections • I am going to the doctor less frequently • I have had fewer hospitalizations • My health has completely changed |
| Professional assistance within the Project | <ul style="list-style-type: none"> • The therapy has helped my child improve • I have confidence in them • I have received a lot of help from them • The professionals have helped me learn about disability • They try to give us simple explanations |
| PSYCHOLOGICAL IMPROVEMENTS | |
| Strategies | <ul style="list-style-type: none"> • My child's behavior has improved • I am putting the training sessions into practice and my child is learning to put objects in order • I do exercises to control drooling • My son now listens when I tell him to do something • I am practicing the stimulation exercises in the home • I am more aware of my pressure points and relieve pressure more frequently • I have improved my nutritional habits • The Project has helped me not to over protect my child |
| Knowledge Awareness | <ul style="list-style-type: none"> • We have learned to manage fever without running to the doctor • I have more knowledge about disability • Now I know how to identify the behaviour of the children • I have learned how to take care of my body and to have better quality of life • The workshops have taught me how to take care of my body • I learned how to do catheterization • I have more knowledge about urinary tract infections and catheterization • The training sessions have helped me increase my ability to function |
| Commitment | <ul style="list-style-type: none"> • I have more commitment to learn in the meetings • Through strength of will I have improved the situation for my disabled children • I feel very committed • My family now knows more about disability and helps me a lot |

| | |
|--|--|
| Acceptance | <ul style="list-style-type: none"> • I have learned to like myself and to not feel alone • I now love my child the way he is. I see many beautiful things in him and am happy to have him in our home. • As a result of sharing with others, I can accept my disability • I have more liberty • Now I am happy and live better |
| SOCIAL | |
| Sharing Experiences | <ul style="list-style-type: none"> • There has been collaboration and union with people outside of the family • There has been union and understanding in regards to disability • My life changed when I got to know ASODISPIE • I learned to know other people with disability and now I see things differently • We get along better with the other members of the Association • I like to participate in the meetings and in ASODISPIE • I have progressed with my daughter because there are other children with the same disability in ASODISPIE |
| Independence and achievements of children | <ul style="list-style-type: none"> • We have permitted our child to be more independent • Now we treat her like a normal child • Now he eats normally and independently • Now he is going to school • Now he walks • Now he knows many things • Now he recognizes his surroundings • She is a little more obedient; knows how to receive small requests |

Specific reports of improvement

- A mother in the CP group demonstrated her improved ability to perform the home program in successive sessions. She states that her son is able to sit better and his relationship with his siblings has improved as a result.
- At the beginning of the project children in the DS group avoided social interaction by hiding their faces. Now, two of these children are so confident in social environments that they perform dances during celebrations in ASODISPIE. Some of the other children will also dance, but with their backs to the audience, for example.
- A mother from the SB group, who had experience in performing intermittent catheterization (IC) with her child, counseled another mother in the group who was fearful to catheterize her daughter at home. The second mother gained the confidence to perform the procedure a constant basis. Her daughter has not had urinary tract infections since implementing IC and the number of diapers she requires has reduced.
- A man with SCI has more confidence in managing his disability, improved independence and mobility and is very motivated to learn about self care. His comment was that being part of ASODISPIE and participating in the project has helped him accept his disability.

Issues raised by the evaluation

The participants, group leaders, facilitators and the professional group were concerned about poor attendance. The participants have been inconvenienced by cancellation of some sessions because only one or two people attended. The professionals are also frustrated by participants who fail to attend sessions and thus lag behind the others in learning about self care. Equally frustrating is the tendency of people to show up 30 - 60 minutes late for the sessions. Suggestions to build more commitment to the project were:

- Development of projects that would build commitment within ASODISPIE
- Financial assistance for transportation
- Provision of a schedule of topics beforehand
- Sessions that are more dynamic, with more games and recreation
- More emphasis on prevention
- More involvement of extended family members such as aunts and uncles
- More involvement of group leaders to motivate people in their groups to attend and to practice self care

Impact of the project on ASODISPIE

The project has had several beneficial effects on the organization. It has helped build leadership skills, unite association members, build a spirit of collaboration between association members and collaborating professionals, and build a sense of confidence within members. Improved self esteem was evident in the two celebratory events held by the Association in October 2007 - Day of the Disabled and Halloween. This year members of the association provided all of the entertainment. They danced, read poems they had composed, sang songs and displayed their handiwork. They painted backdrops for skits and made costumes that were out-of-this-world. These events were demonstrations of ability, cooperation and integration. Their eagerness to perform before others is a definite change from the past where they were reluctant to become involved in activities.

Gender relations and conflict

Gender relations and conflict have not been significant issues within the groups. However, as they are issues in society in general, training sessions have been given on conflict resolution and

communication. Skits have been valuable in terms of leaning about societal tendencies such as “macho” behavior.

The Professional Group

Two physical therapists, an occupational therapist, a speech language therapist, a nurse, a doctor, a nutritionist and two lawyers have given training sessions in 2007. The four therapists are employed by the Association and the remainder are professionals who have a personal contact within the Association and have agreed to contribute. The majority of the training has been given by the therapists employed by ASODISPIE, which facilitates follow-through with the participants and planning of training sessions with the project facilitators. The therapists participated in the development of the strategy presented in Table 3 and were sensitive to the facilitators’ request to engage in more practice during the sessions. Practice plus theory was a shift in the customary training method of giving talks. The shift to include practice has increased participation and encouraged group members to continue the activities at home. The practice component has also benefited the professionals because it has helped them to increase their understanding of the participant’s needs, to reduce their use of medical terminology and has provided an opportunity to follow progress in the participants. Future plans include for the therapists to evaluate each participant and to develop a Home Program with them. The program will be recorded in the participant’s notebook to serve as reference for both participant and professional to determine progress. They also plan to incorporate more group therapy into the therapy program for the participants.

The four therapists participated in the evaluation and reported that the project has motivated them to work in a different way. In the past, a mother brought her child for therapy and waited while the therapist worked. Now the mother (or other family member) is part of the therapy team. Therapy is also done on a group basis. As a result they have seeing the following changes:

- Improvement in the participants practicing self-care activities in the home
- Involvement of family members other than the mother.
- Families are sharing their experiences with each other
- There is more team work between the professionals
- The professionals have increased job satisfaction

- The professionals have become more creative and resourceful in their work

Areas to remain under medical supervision

The nurse was instrumental in providing guidance regarding the areas that should stay under the care of health care professionals. She advised the participants that medication should remain under the supervision of the doctor and that they should not self medicate. Both the type of medication and the dosage should be prescribed only by a doctor. She also taught the participants how to read a basic urinalysis and suggested that they have all the pertinent analysis performed before going to the doctor for diagnosis and treatment. In this way, they could speed up the process.

Recognition of Expertise

The professionals recognize that people with disability have acquired skills to improve their self care and are impressed with the gains they have made to date. They do not yet see them, however, as potential teachers of others and have not invited disabled people with experience to share their knowledge with other people with disabilities.

The recognition of knowledge and experience amongst the focus group varies. One man with SCI, for example, readily acknowledges that the orientation he received in the SCI group has helped him to increase his knowledge of his condition and to make improvements in self care and independence. Interestingly, the sessions have attracted people of other disabilities and some have attended sessions out of interest.

Historical Factors Affecting the Project and Disabled People

In conclusion, I would like to offer some contextual information that may be useful in interpreting the results. It is my opinion that this project has been affected by pre-existing cultural norms and attitudes regarding disability, and these have affected disabled people, the medical system of Santander and health care professionals.

The state of Santander does not have a rehabilitation facility or a solid rehabilitation program in a general hospital. As a result, there is no central resource regarding disability. Although there are specialists who offer service for particular concerns, there is no capacity-building facility with

emphasis on rehabilitation for professionals or the public. As a result, the majority of participants in the project have received little orientation in regards to their condition.

The disability law of Colombia was passed in 1997 and it has helped to bring awareness to disability issues. But it takes time for attitudes to change. Societal attitudes prevalent today teach that a person with disability will not amount to much; that it is important to take care of them and to protect them, but that is all. They are not treated with any kind of normalcy and nothing is expected of them.

The facilitators of the project encountered this type of attitude amongst the participants. It was a revelation to parents of DS children that the children could learn something. Similarly in the other groups, it was necessary to build awareness re possibilities first before making advances in teaching. The attitudes amongst members of ASODISPIE have changed sufficiently so that the Day of the Disabled celebration featured the 'abilities' of their members rather than asking an outsider to perform the entertainment. This year, their members have been involved in shoe making, painting classes and in dance, and these activities have built a sense of confidence not only in the disabled person but also in family members.

Cultural attitudes toward disability also seem to have affected the health care system and the formation of health professionals, in that disability has been given low priority. Even now, health insurance companies refuse to offer products and medicines as required by the health law, forcing disabled people to take legal action. The teaching in medical schools re disability is sparse and thus general practice doctors are largely ignorant about the issues common to disabled people. This ignorance accounts in part for the negative experience disabled people have had when visiting the clinic and thus their reluctance to seek medical assistance for problems in a timely manner.

The low priority given to disability by health care professionals may have been one factor in the difficulty we experienced in forming a professional group. The professional individuals who committed to the project in 2006 did not attend meetings with regularity although some of them reviewed the list of needs developed by the focus groups before drifting away. In April 2007

ASODISPIE signed an agreement with the local hospital that a doctor, nurse and social worker would participate in the project. But it turned out that the people who were to fill the role of trainer kept changing, thus reducing the consistency necessary to achieve the objectives of the project. In the end, ASODISPIE found professionals outside of the public system to hold training sessions.

To conclude on a positive note, this project has been extremely beneficial to ASODISPIE and to its membership. It is beginning to fill a void that has been felt by the Association membership since its inception. The Board of ASODISPIE is very happy with the results to date and is looking forward to continuing the process of learning in 2008.

Acknowledgements:

I would like to thank AIFO and DAR for their leadership of the project and facilitation of the meeting in Rome/07. The project has been a wonderful tool for development on an individual level for all involved as well as for the Colombian and Canadian associations.

I would like to acknowledge the usefulness of “Outcome Mapping” as a tool to provide guidance, structure and timeframes for the project. It has helped us stay on course.

I would like to give a huge bouquet to Rocío Nuñez and Ofelia Buitrago, the local facilitators of the project. They have been unfailing in their dedication to realizing the aims and objectives of the project. I would also like to express my sincerest appreciation to Henry Tabares, President of ASODISPIE and Oscar Guevara, treasurer, for their on-site management of the project.

Lastly, I would like to express my appreciation for the financial assistance we have received from the Christopher Reeve Foundation, who provided matching funding in the first year; the Alberta Wild Rose Foundation, who provided matching funds for the second year; and the supporters of the Canadian Association for Participatory Development who provided the base funding in the first and second years.

Appendix

NEEDS AND NECESITIES IDENTIFIED BY THE FOCUS GROUPS

March 20, 2006

| Categories | Down Syndrome |
|--|--|
| Improving medical care | Needs that require the most attention: |
| | Orientation about raising the child with Down Syndrome |
| | Knowledge about risks factors |
| | It appears that the parents are not aware of any risk factors |
| | Most common complaints |
| | Colds and eye irritation. |
| | Treatment in the home |
| | Don't take medicine and don't know how to manage behaviour |
| | Treatment of complaints |
| One of the fathers demonstrated to his wife that their son could go to the corner store to buy what he wanted. | |
| Ways in which to reduce complaints | Ways to improve health care |
| | It is important to be consistent in therapy because the therapy helps the child become more functional. |
| | Determining when to visit the health centre |
| | Rarely go to the health centre. Don't visit any professional with any regularity. |
| | Family action regarding disability |
| | Some families over-protect the child. When the child misbehaves the family tends to give into the child, doing what he/she wants and this reduces the authority of the parents. |
| | The source of knowledge was empirical or from a professional |
| | Recognize that they don't know how to treat their children. They escape frequently, don't control their sphincters, have aggressive behaviour towards their friends and don't respond to commands. |
| | Areas where they need more clarification |
| | The most severe problem is conduct. They have received little information about Down Syndrome and about how to educate their children so they become more independent. |
| | Ways in which to reduce complications |
| | It is difficult to accept that they need to treat them as normal children. They recognize that the children need a lot of stimulation in order to learn, but they don't know how to do it. |
| | Professional assistance to reduce complications |
| Orientation on how to give them more and better stimulation so they can gain more functionality. Reducing the over-protection within the family. Guidelines for raising children with Down Syndrome. | |
| Experiences in reducing complications | |

| | |
|--------------------------------|---|
| | Depending on the severity of the disability, the child may be delayed in learning to sit, eat, dress and control the sphincters. |
| | Ways in which to seek medical attention |
| | It is important to receive psychological orientation to know how to behave when the child acts out. For example, a girl was forced to sit on the toilet and now she soils her panties because she is afraid of the toilet. |
| | Services used frequently |
| | Physiotherapy and speech |
| | Ways to improve health services |
| | When a baby is born the professionals should provide orientation about the Syndrome, teach parents how to stimulate their child, tell them when the child may be in danger and to visit the health centre. None of the parents were given this orientation; it was up to them to deal with the difficulties on their own. |
| | Ways in which to cope with disability |
| | It is very complicated. We would be lying if we said we are managing well. Around us, people treat the disabled child as “poor little one” (a sentiment expressing that the child is helpless and incapable) and this invalidates our actions. |
| Improvement in Quality of Life | Appropriate medical attention |
| | One child didn't let the dentist examine her and she needed to be seen urgently so they went to another dentist and she let this dentist do everything necessary. |
| | Ways in which to improve the condition of the person with disabilities. |
| | The children with Down are in school but they are not learning very much. Some parents say that their child takes orders from other people, but not from them. At the moment they think they haven't raised the child well and think twice before taking him/her out because of poor behaviour. Some children are integrated with the family but don't have friends to play with. |

| Categories | Spina Bifida |
|---|--|
| Improving medical care | Needs that require the most attention: |
| | Prevention of scoliosis and kypho-scoliosis so the children to improve functionality. Control of subluxation of the hip. |
| | Knowledge about risks factors |
| | It is important to empty the bowels daily so infection does not pass to the urinary system or the colon does not become inflamed, or to prevent obesity. Control of the sphincters is important to avoid infections which can put the person's life at risk. |
| | Most common complaints |
| | Inflammation of the throat, respiratory allergies, reflux. |
| | Treatment in the home |
| | To avoid skin breakdown, some mothers put olive oil on the skin. One child lost a kidney because the mother thought she knew how to treat the complaints of the child and when they went to the health clinic it was too late. On the other hand, mothers can't always supervise the child so carefully to know what is happening and when a condition is severe enough to visit the health center. |
| | Treatment of complaints |
| | It is important to understand the behaviors of the child so action can be taken when they behave out of the ordinary due to a fever (for example). Should smell and observe the color of the urine. |
| | Ways to improve health care |
| | Take the child to the neurologist, urologist and orthopedist and others on a regular basis although it is difficult when the children become adolescents because they become insular and aggressive. |
| | Determining when to visit the health centre |
| | One child should visit the pediatrician regularly because of poor nutrition although this isn't common in children with Spina Bifida.. |
| Family action regarding disability | |
| Leaving the child with a soiled diaper for a long time increases the risk of infection and skin breakdown. Some families have negative attitudes and this limits the independence of the child. | |
| Ways to reduce complications | The source of knowledge was empirical or from a professional |
| | We recognize that we haven't made use of the professional orientation we were given and this has made the process more difficult. |
| | Areas where they need more clarification |
| | Why some children have a delayed development and others have a speedy development. |
| | Ways in which to reduce complications |
| | The professionals teach us to treat the complaints of the children so that we aren't going to the health centre as frequently. |
| | Professional assistance to reduce complications |
| | Surgery for club foot, tight tendons etc and to orthopedist for braces. |
| Experiences in reducing complications | |
| Professionally they believe that they should do tendon lengthening operations when the child is older, so the surgery does not have to be repeated. | |
| Improvement of Quality of Life | Ways in which to seek medical attention |

| | |
|--|--|
| | Services used frequently |
| | It is important to clarify that these children do not use primary medicine services, but see specialists. |
| | Ways to improve health services |
| | To listen to the person with disability, to talk clearly, to take more interest in knowing more about people with disabilities and their needs. |
| | Ways in which to cope with disability |
| | It is important to seek psychological help for the nuclear family so they can learn to manage the new situation. Faith is fundamental to the situation. |
| | Appropriate medical attention |
| | It is important to visit the gastroenterologist because some children eat very little. |
| | Ways in which to improve the condition of the person with disabilities. |
| | It is important to give the child the opportunity to develop, to strengthen their childhood development. Socially they should be helped because they feel isolated due to their condition, to take them into account during play. Learn to control the tendency for sympathy because this does a lot of damage to the children as well as to their parents. Take them to the pool for relaxation. Allow them to relate with other children. |

Note: These remarks came from 2 separate groups of children and adults with CP. The responses are on separate lines.

| | |
|---|---|
| Categories | Cerebral Palsy |
| Improving medical care | Needs that require the most attention: |
| | Therapies Some children lack love and have been neglected. |
| | Knowledge about risks factors |
| | One boy didn't develop his immune system and they have to be very careful. Some have heart problems. Urinary infections should be controlled so the kidneys do not get infected. |
| | Most common complaints |
| | Convulsions. They don't get sick much. |
| | Treatment in the home |
| | Try to give them adequate medications, water for nerves and try not to bother them so they don't become violent and have convulsions. Some just try to find a comfortable position but it is not always the best posture. |
| | Treatment of complaints |
| | It is important that the mother receive orientation about the disability since the time of birth so she knows how to treat him/her. Orientation about rehabilitation or a person who can help the child walk as was the case of one parent who was very unhappy with the results of therapy because the child did not make progress. All the children with CP have mental retardation secondary to epilepsy. In others, microcephalia causes severe complications such as prematurity at 5 months, failure of one kidney to develop, convulsive syndrome, intestinal problems, scoliosis due to poor posture, psychomotor problems. Others have ataxia, spasticity, learning disability. They don't know how to manage these problems. |
| Ways to improve health care | |
| One woman has 2 children with disabilities; one is aggressive and violent with the family, damages things in the house. One brother suggested that he be given a psychiatric drug but the point is that they don't know how much to give the child. If they increase the dose when the child is in crisis, he/she | |

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| | <p>becomes drowsy for about 5 days and cries a lot afterward. Recommend that they visit the doctor because auto-medication has its consequences. The woman does not comprehend that the child has grown up and requires respect for personal space.</p> <p>Determining when to visit the health centre</p> <p>The adults with disabilities treat the common complaints in the home. Others visit the health centre for health maintenance.</p> <p>Family action regarding disability</p> <p>The family treats the PWD as a child and not according to his/her age. For this reason they haven't taught him/her to be responsible and this has resulted in the child not complying. This is mainly the mother's problem because she thinks of her child with pity and over protects him/her. This attitude of pity is cultural. They have a passive attitude and don't stimulate. On the other hand they don't permit them to do things that they think the child is incapable of doing, although some mothers have let loose a bit and let the child do some things.</p> |
| Ways to reduce complications | <p>The source of knowledge was empirical or from a professional</p> <p>Some say that they have received very little professional orientation. They feel they are passive in front of professionals and comply with their recommendations but don't understand the significance of the information.</p> <p>Areas where they need more clarification</p> <p>Don't know how to stimulate their children to improve their condition. They feel parents lack knowledge of how to help in the rehabilitation of their children.</p> <p>Ways in which to reduce complications</p> <p>Receive a good orientation about what to offer to the children One mother blends all food for her child because he/she cannot take solid food. Drug administration to avoid convulsions.</p> <p>Professional assistance to reduce complications</p> <p>Very few comments. See that the therapy is important, but don't feel involved in that. The families feel they need orientation</p> <p>Experiences in reducing complications</p> <p>It is fundamental to know the symptoms before convulsions, for example, so the child will not get hurt. Some precursors are glassy eyes, stress and headache.</p> |
| Improvement of Quality of Life | <p>Ways in which to seek medical attention</p> <p>Few visit the health centres</p> <p>Services used frequently</p> <p>Just control of convulsions Neurology for convulsions, ear, nose and throat specialist, respiratory medicine, physical medicine, orthopedist, optometrist.</p> <p>Ways to improve health services</p> <p>No response Some mothers feel regular medical checkups are important although they haven't had very good experiences with the professionals because some surgeries have increased the disability (convulsed in the surgery and got worse).</p> <p>Ways in which to cope with disability</p> <p>Despite convulsions, one young person wanted to improve him/herself so ASODISPIE gave him/her the opportunity to work in the park. The local school has opened their classrooms to children with disabilities and take into account the child's disabilities in terms of learning speed using a method called CAFAN which is adult education. The child is very enthusiastic but doesn't forget his/her medication because his/her convulsions are very strong and</p> |

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| | prolonged. |
| | Appropriate medical attention |
| | Don't visit professionals except for epilepsy, but not frequently. Depending on the condition of the child, some don't go to the health centre. |
| | Ways in which to improve the condition of the person with disabilities. |
| | It is important to take these children into account, for the school to stimulate them to study and that they provide the mediums necessary to improve their academic learning. One sister teaches the mother that the child can help around the house and the child is happy because he/she has a role in the family. One mother called the family together after the last meeting to tell them to call the child by name and not by nickname. Most families have the problem that they don't teach their children to take responsibility and fail to notice that they are adults. The mothers realize that they over project their children and don't allow them to help with the house chores, especially when they have difficult behaviors that they don't know how to control. What they do is scold them, make them feel bad. They need the family to get more involved in the process because sometimes the mothers feel very alone in this process with their children. |

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| Categories | Spinal Cord Injury |
| Improving medical care | Needs that require the most attention: |
| | Neglected pressure sores that reach to the bone and lead to removal of the infected bone. A pressure sore that is the most difficult to heal is on the coccyx. When pressure sores don't heal, they are surrounded by dead tissue and when this happens, it should be debrided for it to close. |
| | Knowledge about risks factors |
| | One participant uses laxatives frequently to evacuate the bowel which causes loss of intestinal flora which can lead to peritonitis and a vasectomy in which they removed the colon. |
| | Most common complaints |
| | Chronic pressure sores |
| | Treatment in the home |
| | Should take care of boney prominences but if they (pressure sores) don't close well, surgical tape should put on in the form of a butterfly. The family uses herbs to combat infections. |
| | Treatment of complaints |
| | To receive a good professional orientation and protecting the lesion. |
| | Ways to improve health care |
| | It is important to manage constipation, to learn to eat well, lots of fruit. Also it is important to drink lots of water to keep the kidneys functioning well. In addition it is important to know where the reactions are coming from, for example when you have a urinary infection you feel an itch in the lips or shivers (individuals can experience very different sensations). |
| | Determining when to visit the health centre |
| When a pressure sore with infected bone smells, it is important to visit the health centre. | |
| Family action regarding disability | |
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| Ways to reduce complications | The source of knowledge was empirical or from a professional |
| | Professional: A high level lesion affects all the limbs. C affects the cervical spine and the lumber and the hips; the numbers 1-4 is the most severe because it affects the respiration and you have to breathe bronchially. Also, it depends how a person is treated at the accident site, if they try to stand the person. |

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| | <p>The T lesion affects the thorax up to the umbilicus and from that point down, it is the lumber.</p> <p>Areas where they need more clarification</p> <p>Ways in which to reduce complications</p> <p>PWD are not in the habit of visiting the health centre even though they know they should. It is important to avoid poor posture in order to reduce scoliosis. They say it is important to sit a person in good posture from the beginning because this helps to maintain good posture, even more so because the sedentary position increases the belly.</p> <p>In regards to scoliosis, the physiotherapists provide orientation but no don't prevent the problems like Marlene Wiens does with the workshops that help to prevent scoliosis.</p> <p>Professional assistance to reduce complications</p> <p>They need psychological help to combat certain bodily sensations that, when they look for the cause, they can't find one. Some feel heat in the legs, but when they are tested they can't feel. They say it is phantom pain. How to control involuntary reflexes and tickles, etc.</p> <p>Experiences in reducing complications</p> <p>It is important to know how the body behaves in order to know when to urinate, to evacuate the bowels; to learn how to manage the chair. The worst is to feel sorry for yourself.</p> |
| Improvement of Quality of Life | <p>Ways in which to seek medical attention</p> <p>Services used frequently</p> <p>Ways to improve health services</p> <p>Ways in which to cope with disability</p> <p>It is fundamental that the person blocks out the past and lives in the present. One of the things that affects a person the most is the loss of sexual sensitivity – one doesn't think of being resourceful, about how to do things differently; because we think that we have to walk, we don't learn skills in managing the chair. We lose time by crying and thinking, "why me?". Although it is very tough, it depends on the attitude one has; faith is important but we should help ourselves; it is important to live the process. The other thing that is difficult is the lack of sphincter control because a person has two options: feel sorry or do whatever possible to go to the bathroom. Not only the person but also the family should receive psychological orientation.</p> <p>Appropriate medical attention</p> <p>It is important to receive advice from professionals or from the self-help group because it is serious if a person fills with an inferiority complex which feeds the feeling of inability amongst others; when you go out you feel that you can't do it because of fear. Above all it is important to manage complications, because a friend didn't take care and died.</p> <p>Orientation about the injury. The people in the group have the following lesions: T8, C6, C7, T10, T11 y T12</p> <p>Ways in which to improve the condition of the person with disabilities.</p> <p>It is important to form relationships with others and not to turn inward, to become involved in sports, learn to be more independent, to work and to psychologically leave the past behind, stop living on memories and crave sympathy because this is what embitters a person.</p> |