



Parent Participation in Los Pipitos Nicaragua

Factors contributing to the high level of parent participation in Los Pipitos
Nicaragua

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Samenvatting

Dit onderzoek richt zich op de factoren die gezorgd hebben voor het hoge niveau van ouderparticipatie in Los Pipitos, een organisatie van ouders voor kinderen met een handicap in Nicaragua.

Het model van participatie van Shepard en Rose (1995) bevat vier niveaus van participatie: communicatie, verbeteren thuis situatie, vrijwillige inzet en advocacy. Dit model is gebruikt om de term ouderparticipatie te structureren in dit onderzoek. Interviews, observaties en focusgroepen werden uitgevoerd in acht projecten van Los Pipitos van januari tot en met april, 2012. Tevens werden de statuten en het ontwikkelingsplan van de organisatie geanalyseerd.

Inbedding in de gemeenschap, beleid betreffende participatie en de mate van professionalisering beïnvloedden ouderparticipatie sterk. Inbedding in de gemeenschap en beleid betreffende participatie hadden een positieve invloed op ouderparticipatie. Het effect van de mate van professionalisering was echter ambigu. Professionele therapeuten die ouders ondersteunden in de therapie voor hun kinderen verbeterden de participatie op niveaus van basis communicatie en verbetering thuis. Met uitzondering van Ocotal en Distrito VI, waar ouderparticipatie juist verminderde door professionalisering op het vlak van therapie. Professionalisering op een niveau van organisatie en beleid verminderde de ouderparticipatie in twee projecten, omdat professionals de rol van ouders overnamen. In andere projecten probeerden professionals de ouders te ondersteunen in de organisatie van het project. Deze ondersteuning zorgde er voor dat participatie in deze projecten toenam.

Abstract

This study focuses on factors which contributed to the high level of parent participation in Los Pipitos, a parent organization for children with a disability in Nicaragua.

The participation model of Shepard and Rose (1995) encompasses four levels of participation: basic communication, home improvement, volunteering and advocacy. This model was used in this study to structure the concept of parent participation. Interviews, observations and focus groups were conducted in eight projects of Los Pipitos between

January and April 2012. Also the constitution and development plan of the organization were analyzed.

Embedding in the community, participation policy and amount of professionalization strongly influenced parent participation. Embedding in the community and participation policy had a positive influence on the parent participation but the effect of the amount of professionalization was ambiguous. Professional therapists supporting parents in therapy for their children improved the participation on the levels of basic communication and home improvement. Exceptions were Ocotal and Distrito VI, here participation of parents decreased because of professionalization in the therapy. Professionalization on an advocacy level decreased the parent participation in two projects, because professionals took over the role of the parents. In other projects professionals tried to support parents on the advocacy level of the project. This support increased parent participation in these projects.

Introduction

Nicaragua is one of the poorest countries in Central America: 46,2 % of the population lives under the national poverty line (Worldbank, 2005). According to Bradshaw and Linneker (2003), 44% of the people are living on less than a dollar per day and 75% on less than two dollars per day. In Nicaragua the prevalence of disabilities is 10,3 % (Mont, 2007). Dudzik, Elwan and Metts (2002) state in their review that the major causes for disabilities in developing countries are malnutrition, communicable diseases, low quality of perinatal care and accidents. According to this review, poverty also increases the risk on developing a disability. In Nicaragua, the Revolution and the Contra War as well have been causes of disability. Not only accidents related to this war caused disabilities. Other equally important causes of disability were: severe malnutrition, lack of medical services, prevention and bad sanitation (Montes and Massiah, 2002).

In the recent past the Nicaraguan society did not accept children or adults with a disability; ignorance and prejudice were common towards this group. Services or therapies were not available for children with a disability (Los Pipitos, 2012a). Therefore, a group of parents from children with a disability organized themselves and founded the organization Los Pipitos to provide services for these children. The parent participation in Los Pipitos is high; the parents run the major part of the organization themselves (Los Pipitos, 2003).

The participation in the organization Los Pipitos is not only formed through parents. In addition to parents, members of the extended family also play an important role in participation (Los Pipitos, 2003). Therefore, both participation of parents and family members other than parents will be investigated and will be referred to as parent participation in this study.

According to empirical work of Hartas (2008) parent participation improves the well-being of children; by being closely involved parents influence children's rehabilitation process and their social and emotional development. Hence, the participation of parents is important for the positive development of the child.

It would be useful for other similar organizations to know in which way this participation of parents and other family members is established and maintained in Los

Pipitos. Therefore, the aim of this study is to identify the current level of participation and factors which influence parent participation. The research question of this study is: *'Which form does parent participation take in Los Pipitos and how do local circumstances and participation policy influence this participation?'*.

Project description of Los Pipitos

Los Pipitos is an organization of parents, families and friends of children and youngsters with a disability who provide help for these children, youngsters and their families. In 1987, 21 parents of children with a disability invited families of children with disability to organize themselves voluntarily (Los Pipitos, 2012a).

The mission of the organization is to make families of children with a disability work to create a community with better conditions and equal opportunities for children with a disability. Families, the community, civic organizations and the state are sensitized according the rights of children with a disability. The goal is to implement and legalize policy, programs en specialized services. These tasks are a shared responsibility of family members and professionals. Parents and their children who become member of Los Pipitos receive privileges in care and support. Nevertheless, for parents and children who are not a member some services are available as well (Los Pipitos, 2012b).

As of now there are 86 active projects of Los Pipitos in whole Nicaragua. A project is called a capítulo when at least 50 families are organized together to provide help for their children with a disability. A capítulo has a board (Junta Directiva Municipal) which is responsible for the organization of the project. 50 members have to participate in the election of the board. The president of this board is a parent of a child with a disability and the treasurer someone from outside the organization. A project which does not have 50 parents, but does offer some therapies or activities is called a pre-capítulo. Instead of a board, pre-capítulos have a parent commission. In this study both a capítulo and a pre-capítulo of Los Pipitos will be called a project (Los Pipitos, 2003).

Four programs are present to accomplish the mission of Los Pipitos (Los Pipitos, 2012c).

1. Sensitization and promotion of the human rights

This program is aimed at the change in Nicaraguan society concerning the human

rights of people with a disability and influencing policy and legislation. First of all, the organization tries to unite parents of children with a disability to inform each other about these human rights. Parents who do not make their children integrate in society and/or are not stimulating the development of their children are motivated by other parents. Second, the organization provides lectures and advertisement in the entire country to promote the rights of children with a disability.

2. Learning programs for families

Prevention and rehabilitation are important parts in the organization and they are based on two ground rules. First of all, the participation and dedication of parents is essential in the rehabilitation of the child. Second, the support needs to come from the community to make this process succeed. Therefore, the program contains several elements.

Los Pipitos has centers for early education and regional centers for rehabilitation and early education. In these centers rehabilitation services are offered. The regional centers provide additional medical and diagnostic assistance for children and here volunteers are trained. Furthermore, a medical pedagogical institute in Managua is present, which provides diagnostic and rehabilitation services for people in entire Nicaragua. To reach the more rural parts of the country Los Pipitos has a mobile brigade.

Almost each project arranges learning groups for parents. Trained volunteers manage these groups, where parents exchange experiences and gain new knowledge about the disability of their child. The development of the children at home is stimulated through these groups.

3. Programs for social integration and community enhancement

Los Pipitos not only provides medical and rehabilitative care for children with a disability, they also try to promote their integration in Nicaraguan society. The integration of children with a disability in education and in working life are parts of this project. In addition, activities related to sports or culture are organized to stimulate the integration of these children. Once a year, a cultural or sports festival is held to make the Nicaraguan society aware of Los Pipitos and her activities. Parents and children from almost every project participate.

4. Program for development of associative skills

To assure leadership capacities of board members, leadership trainings are organized. This is arranged by national staff members, who visit a project to provide trainings. In these trainings a participative method is used, participants have to participate in role plays and evaluate their own activities in exchange with other parents.

Theoretical framework

Definition and importance of participation

Zimmerman and Rappaport (1988, p. 726) describe participation as “involvement in any organized activity in which unpaid individuals participate in order to achieve a common goal”. When it comes to the participation of parents, these terms are divided in parental involvement and parental participation. According to Fan and Chen (2001) and the theory of Ho Sui-Chu and Willms (1996) parental involvement contains the basic obligation of parents and the involvement of parents in daily routines of the institution and at home. Bray (2001) and Suzuki (2002) refer to parental participation when there is an influence of parents on organizational and policy level of the organization. Since in this thesis the two explanations are used together, the term parent participation will be used to cover both definitions.

Empirical studies (Coyne & Cowley, 2007; Epstein, 2001; Hartas, 2008; Ketelaar, Vermeer, Helders & ‘t Halm, 1998; Poirier & Simard, 2006) show that parent participation in different institutions like school, medical care or daily treatment, contribute to more effective care for children. Granvolt, Woltman and Hoher (1990) explain in their review the important role of family members in providing care and treatment for those children who require extensive and frequent exercise and/or treatment at home. Although some of this literature is retrieved from studies in educational settings, the information might also be applicable in other settings, such as daily treatment.

Empowerment and its influence on parent participation

According to Van 't Rood (2012) empowerment is “the ability of people to direct and control their own lives, but with the self organization to construct a caring, responsible and safe environment”. To come to constructive changes in their environment this ability has to be adjusted to the existing system and structures of power (Inglis, 1997;

Ansell, 2005; Hur, 2006). Berger and Neuhaus (1977) describe empowerment as a term which refers to the control people have regarding their own life and their participation in the processes inside their community (Ansell, 2005; Katz, 1984; Rappaport, Swift & Hess, 1984;), which can be seen as a combination of the two first definitions. Both Judge (1997) and Trivette, Dunst, Hamby, and LaPointe (1996) define a strong and significant relationship between the empowerment of parents and their participation in help-giving practices. These studies found out that more empowered parents were participating more in help-giving practices.

Shepard and Rose (1995) describe in their theoretical study how empowerment and parent participation are related. The more parents feel empowered, the more they are likely to participate. A higher amount of participation is achieved when parents acquire the knowledge, skills and trust in others necessary for empowered control over their own life.

According to their theoretical model (Shepard & Rose, 1995) parent participation takes place in multiple levels: basic communication, home improvement, volunteering and advocacy. Basic communication contains the initial contact between parents and the professional in the institute who offers care for the child. In this phase parents accept the responsibility they have monitoring their child's progress and reporting this progress to the professional. Parents also may have accepted the information gained by the professional. The next level, home improvement, is focused on improving parenting skills and/or skills related to the child's home-learning environment. The parent must be more committed in this stage and more involved in his personal development as well the one of the child. Volunteering contains the activities which go beyond the home environment, as parents are more involved in the institution itself. The abilities of the parent are important and he or she has to be more confident of their own self. This is because contacts with other parents and people in the institution become more frequent. The level of advocacy focuses on the involvement in local, district or statewide groups. The parent takes part in influencing the policy and procedures or other institutional changes affecting the community.

Shepard and Rose (1995) argue that the involvement and empowerment of parents become more intensive when they follow these four steps. The empirical study from

Reicher, Bickman and Heflinger (2004) made clear that parental beliefs or self-efficacy are indeed reaching the highest level once they learn to assist and interact with other people in a civic or health organization, like children or parents and/ or work with local and statewide organizations. Bloom (1992) adds that only when parents are actively involved in groups or offices which affect changes on a local, district or state level, parents find themselves in the highest level of empowerment.

Conditions for successful participation

Several studies (Hartas, 2008; Ketelaar, et al., 1998) discover that organizations and parents must act in certain ways to reach successful participation in different levels. Ketelaar et al. (1998) reviewed multiple studies and found that through participation of parents the care for children with a handicap is more effective, but only under certain conditions. Several of these conditions are made clear in the model of Wolfendale (1985) which is confirmed in a study of Swicks & Graves (1993).

First of all, according to the model of Wolfendale (1985), parents have to contribute to services as well as to receive them. Other studies (Hartas, 2008; Ketelaar et al., 1998) explain that parents develop self-confidence and responsibility by contributing to services, which makes them more empowered. The chance that parents feel empowered to participate increases by receiving the appropriate services for the problems of their children (Judge, 1997; Trivette et al., 1996).

Second, the model of Wolfendale (1985) states that parents need to be active and need to have a central position in decision-making and implementation of the services. Reiger, Bickman and Heflinger (2004) point out that the extent of collaboration between parents and professionals is related to parents' perceived self-efficacy. Therefore, it is beneficial to approach parents as equal partners to improve their self-efficacy. According to Delgado-Gaitan (1991) this increase in empowerment again leads to better cooperation between professionals and parents. When parents are not in an equal position, they may feel not taken seriously and their participation can decrease (Kellagan et al., 1993). The review of Ketelaar et al. (1998) adds the result that collaboration in setting goals may prevent unrealistic expectations and frustrations of parents and professionals. This study (Ketelaar et al., 1998) also emphasizes the importance of parents being involved closely

in the daily care of the child. Professionals have to teach parents how to establish the care and exercises at home.

Third, according to Wolfendale (1985) parents have to be seen as people who carry the same amount of expertise as professionals do. When professionals acknowledge this expertise, parent participation increases (Poirier & Simard, 2006). Nevertheless, the idea of equality of expertise changed in later studies. Dale (2006), confirms the value of an equal relationship between professionals and parents, but clarifies that this does not mean parents and professionals having the same amount of expertise. Parents have a lot of knowledge and insight regarding the needs and development of their own child (Swicks & Graves, 1993), therefore, they can make a meaningful contribution. According to Dale (2006) this makes them equal to professionals.

Fourth, the model (Wolfendale, 1985) states that parents share responsibility with professionals; they are mutually accountable. The professional and the parent are not separately enhancing the development of the child, but should take responsibility together (Coyne & Cowly, 2007).

Civic organizations and social capital

Los Pipitos, the subject of this study, is a civic organization. The following theories explain how civic organizations are constructed and make it possible to understand the definition of civic organizations.

According to Weinberger (2000), a civic organization is built by social capital. Social capital or a community has been defined by Brown & Ashman (1997, p. 1470) in terms of “relationships that are grounded in structures of voluntary associations, norms of reciprocity and cooperation and attitudes of social trust and respect”. A community is as well defined in other terms. Gusfield (1975) uses two major terms in his theoretical study. The first is the territorial and geographical idea of community: the neighborhood, town or city. The second is “relational”: it does not emphasize the territorial space, but “the quality of the character of human relationship, without reference to a location”. Gusfield (1975) notes that these two terms cannot be seen separately, but Durkheim (1964) observes that society develops community around interests and skills more than around locality. The relational definition of community will be used as the definition of

community in this study, since it corresponds with the definition of social capital.

According to several studies (Brune & Bossert, 2009; Epstein, 2001; Liu & Besser, 2003; Weinberger & Jütting, 2001), social capital plays an important role in the participation in civic organizations. In Nicaragua, a high amount of social capital in organizations improved the level of participation in civic organizations (Brune & Bossert, 2009). Additionally, empirical work from Moser (1998) demonstrates that particularly on poor people, social capital has a positive influence.

This positive influence is explained as follows. An important indicator of social capital is the existence of a local development group; being a member of a network on a local level (Weinberger, 2000). When people are united in local development groups they feel less vulnerable (Moser, 1998) and they are on their way to becoming more empowered. Case studies (Lam, 1996; Ostrom, 1996; Thorbecke, 1993; Uphoff, 1993) show that membership in groups facilitates information exchange and helps building trust and social cohesion. This relation is also mentioned by Moritsugu (2010); shared problems between individuals can result in relationships which contain mutual emotional support. In addition, professionals' involvement within the families increases as well (Epstein, 2001). This form of bonding inside an institution makes it easier for people to participate and/or to maintain their participation (Moritsugu, 2001; Perkins & Zimmerman, 1995).

Weinberger (2000) adds another concept; in her empirical study the costs and benefits of participating on an environmental and personal level are summarized. On an environmental level these are the communication system, time, budget and the institutional structure which surround a person. On a personal level these contain the interesting and searching behavior, attitude towards political and social behavior and perception of power relations. The costs and benefits of participating are explained in the study of Weinberger and Jütting (2001). When a family, for example, is on a tight budget and taking the child to therapy means there is less money to feed the family, the costs of participating in an organization are higher than the benefits. When costs of participating are higher than the benefits, there is none or less participation. When the benefits are higher than the costs, it is more likely that people participate. It is especially difficult to make poor people participate, because most of the times their costs are higher than the

benefits. Therefore, organizations and donors must reduce the costs or increase the benefits, to reach this part of society.

The empirical work of Weinberger and Jüttinger (2001) makes clear that being a member of a social network can be a benefit for people and therefore, is an important determinant for participation.

Current study

The aim of this study is to identify the form of parent participation in Los Pipitos and how local circumstances and participation policy influence the level of parent participation. The literature mentioned above makes it possible to structure the methods and results of this study in order to identify these different elements. The following two sub questions are formulated:

- What is the amount and form of parent participation in the investigated projects of Los Pipitos based on the levels basic communication, home improvement, volunteering and advocacy?

The theoretical model of Shepard and Rose (1995) is used to structure the sub question about the form of parent participation based on the four levels of the model. Additionally, the model is used to see if parents who are present in the various levels show different levels of empowerment.

- What is the influence on parent participation of
a. community embedding,
b. participation policy and
c. amount of professionalization?

The theory of Weinberger (2000) emphasizes the importance of social capital in civic organizations and the four elements of the model of Wolfendale (1985) point out the key role of professionals in parent participation. As a result, this information forms the first and the last of point of this sub question. Additionally, these elements of the model of Weinberger (2000) and Wolfendale (1985) will be used in this study to identify the form of the different projects in this study.

Methods

This study employed document analysis, semi-structured interviews, focus groups and observations. As table 1 shows, eight of the 86 projects of Los Pipitos were investigated, at least one project in every region of the country. Besides selection by location, projects were selected because of the following circumstances; located in urban or rural area, an own or a rented building, high and low levels of facilities offered by the project, high and low levels of parent participation and the recognition as a capítulo or not. The differences between the projects made it possible to compare the results and to see whether or not these factors had an influence on parent participation.

	President Interviewed	Parents	Board members	Key- informants
Nueva Guinea	Yes	2 (interviews)	2	3
Ocotal	Yes	18	2	2
El Sauce	Yes	9	3	1
Potosí	Yes	-	1 (commission member)	1 (national staff member)
León	Yes	8	4	1
Distrito VI	Yes	5	2 (commission members)	1 (paid employee)
San Rafael del Norte	Yes	10	2	2
Bluefields	Yes	-	2 (commission members)	-

Table 1. Overview of investigated projects

Procedure

Two policy documents of Los Pipitos were investigated in the document analysis.

The first document concerned the 'Estatutos' (Los Pipitos, 2003), an explanation of the work procedure of Los Pipitos along with the rights and obligations of members. The second document was the 'Plan estratégico 2008-2012', (Los Pipitos, 2008) which contained future objectives of the organization and the manner in which these were to be reached. The information retrieved from this analysis was used to form topics for the interviews and focus groups. Besides that, the general policy was part of the data since it had an influence on parent participation.

The interviews with board members of the projects included the following topics: conditions of the municipality, form of the project regarding services and recreational activities, the process of rehabilitation, the advocacy part of the project, the levels of parent participation and the use of organization policy in the project (Appendix 1). The interviews with professionals on rehabilitation level contained the same topics except the topics about advocacy (Appendix 2). In the focus groups these topics were the same, but questions were adjusted and topics about feelings/opinions of the parents were added (Appendix 3). Next to these interviews, researchers asked key informants on a national level about the differences between the projects. Additional factors which influenced the participation of parents were asked too. Sometimes these informants mentioned new perspectives which the researchers were not aware of. Therefore, these topics were added to the topic list.

The national staff of Los Pipitos informed the different projects about the visits of the researchers and local staff was asked to organize the focus groups. The researchers asked for participants with different characteristics, as a result the participating people varied in age, time/experience in the organization itself and level of participation. Most of the parents were mothers, because they participated more than fathers in the projects. Sometimes other family members were present as well. The selection of participants for the interviews happened during the visit. Researchers selected additional key-informants at the project, based on observations and conversations. Participants were selected because they had a lot of current knowledge of, and experience with the project. Furthermore, a board member and someone from outside the board were interviewed because these persons had different viewpoints about the project organization. Paid therapists, when available, were included in the interview as well, because they had a

more objective view on the project.

As table 1 shows the focus groups varied in size from five to eighteen parents and 30 interviews were conducted. The big differences in numbers of participants in the projects can be explained by practical factors as time limits, lack of key-informants other than board members and the number of parents who actually were invited and showed up during the focus groups.

One interview is partly used because the record of the interview got lost before the transcription was finished and as a result it was not complete. The interviews were taken individually most of the time, although in some cases because of time limits of participants, interviews contained two or three participants.

The focus groups and interviews were semi structured and conducted with a topic list. At all times the interviews were flexible and occasionally the topic list did not suit the situation of the location. At these times, it was not used completely. The focus groups and interviews took place in the centers of Los Pipitos. Some exceptions came up: one interview was conducted at the workplace, and two at the house of the participant. Observations were free, which meant that the researchers observed therapies and activities in the center and made notes, to describe the situation.

Reliability and validity

Some parents might have given socially desirable answers during the focus groups. This was notable since parents waited on an approval of other participants and therefore answered slowly or let somebody else answer. There were several reasons why parents might have given socially desirable answers. First of all, the presence of a board member might have influenced the answers of the parents, since some parents not dared to be honest. Nevertheless, presence of board members was not avoided. The board members made the participants feel more comfortable, at times they helped explaining questions and gave some extra information. The researchers talked with two presidents in advance when they attended the focus groups to explain them not to give answers, but help explaining the questions.

Another influence on the given answers in the interviews/focus groups was the cultural difference between the researchers and participants. The participants did not want

to be negative about their own project to people from outside. Besides that, the participants knew that the researchers visited Los Pipitos for the Liliane Foundation. This might have increased the social desirability of the answers, because of the gratitude these respondents wanted to show to secure more help in the future. This problem is solved by telling the participants that the researchers were not from the Liliane Foundation but only did a research for this organization. Thereby the researchers created a comfortable atmosphere during the interviews and focus groups. They did so by introducing themselves, starting with easy questions, such as facts about the project and the researchers made clear that there were no good or wrong answers. Still, objective answers by the participants cannot be guaranteed, but researchers checked the given answers with their own observations and as a result reliability was protected.

All the interviews were conducted in Spanish, Nicaragua's official language. This was not the researchers first language. The researchers received training and could express themselves and understand others clearly, but had some help by native speakers with setting up the topic list. One interview is not used because of language differences and misunderstanding between the researchers and the participant. This made the interview not reliable enough.

The interview-topics determined the form of the interview. Therefore, factors which had an influence on the level and form of parent participation could have been missed because the researchers simply did not ask for them. This threat is diminished by stating some extra open questions about factors which influenced the participation in a positive or negative way according to the participants (Appendix 1,2 & 3).

During the study the researchers kept in touch with national staff members, who were important key-informants. Conversations with them were held every now and then to discuss the results so far. During these conversations new topics came up which were added to the current list.

The use of several methods made comparison of the answers possible. At the moment results within a project were inconsistent the researchers tried to check which result was correct. If this was not clear, those results were not used. For example, the results regarding numbers of parent participation were not included in the analysis, since the answers concerning the amount of participation in a project varied highly between the

participants.

Because of these procedures, such as eliminating inconsistent results and creating a comfortable atmosphere during the interviews and focus groups, the reliability of the study is secured.

Results

General information about the projects

Capítulo

Table 2 shows Potosí, Distrito VI and Bluefields not being a capítulo at the time of the study. These projects did not have enough active members or a board. All the other projects were rated as a capítulo. León was the oldest capitulo and has been a capitulo for 24 years now.

	Capítulo	Urban or Rural	Level of poverty in municipality¹	Transport
Nueva Guinea	Yes	rural	severe	-
Ocotal	Yes	urban	low	-
El Sauce	Yes	rural	intermediate	-
Potosí	No	rural	low	-
León	Yes	urban	low	-
Distrito VI	No	urban	low	-
San Rafael del Norte	Yes	Rural	high	-
Bluefields	No	urban	severe	-

Table 2. general information about the projects

Urban or rural

The information given in table 2 combines information given by the participants and observations of the researchers. Managua was the most urban area, followed by León. The other towns were smaller, but Bluefields and Ocotal were also rated as urban

1. Mapa de pobreza extrema municipal por el método de necesidades básicas insatisfechas, Instituto Nacional de Información de Desarrollo, 2005

because they fulfilled a more regional function.

Poverty

Some households lived beneath the international level of extreme poverty in the municipalities where poverty was rated as low. Poverty turned out to be a problem in all the visited municipalities. The level of poverty in the municipalities was highly related to the location of the municipality in the country. Bluefields and Nueva Guinea both were extremely poor and located in the east of the country, which was the poorest area of Nicaragua. Ocotal and San Rafael del Norte were both located in the north, but Ocotal was less poor because employment was higher. The other municipalities were located in the west; here poverty was lower.

Transport

Transport turned out to be a problem for every project. In urban areas public transportation was too expensive, or not accessible for children with a disability. In the rural areas there was not sufficient public transport and parents had trouble reaching the projects.

Amount and form of parent participation in the projects with regard to basic communication, home improvement, volunteering and advocacy

	Basic Communicatio n	Home improvement	Volunteering	Advocacy
Nueva Guinea	-	+-	++	+
Ocotal	+	+	+-	+-
El Sauce	+	+	+	+
Potosí	--	--	--	--
León	+	+	++	++
Distrito VI	+-	+-	--	--
San Rafael del Norte	+	+	+	+
Bluefields	+-	+-	-	-

Table 3. overview of parent participation in the projects

Amount of parent participation

Table 3 shows information about the amount of parent participation in the projects. In Potosí, Distrito VI and Bluefields parent participation was extremely low; only a few parents were active. Bluefields and Distrito VI did offer some kind of therapy and several activities. In Potosí the project only offered a few activities for adolescents.

In Nueva Guinea and León parent participation was high, the majority of the members was active at the levels volunteering or advocacy. Respondents in Nueva Guinea even mentioned that all the active members participated at the levels volunteering and advocacy. On the other hand, observations showed some parents who came occasionally to the center but practiced with their children at home, these parents were situated in the level home improvement.

In El Sauce and San Rafael del Norte parent participation was intermediate. Members who lived close to the project participated on the levels of volunteering and advocacy. Parents who lived in remote areas were willing to participate, but through difficulties with project access they participated less. In Ocotal, participation on basic communication and home improvement was high, but only some participation in the levels volunteering and advocacy was present.

Form of parent participation



Figure 1. An example of parental involvement; mothers doing physiotherapy with their children

In the different projects, parents had an active role in the therapy of their children. Professionals or trained parents instructed the parents in which way to work with their children and parents were supported in this process. Distrito VI and Ocotal had professionals who sometimes took over the task of the parents. In all locations, except Potosi, parents participated in parent learning groups to learn more about the disability and how to work with their child at home.

Some parents, especially in Ocotal, did not practice at home; at times they were not even active during the therapy. Furthermore, a lot of parents in Ocotal forgot their appointments or did not come to their appointments on time.

Activities on a voluntary level mainly concerned the organization of activities, helping with activities in the different projects, cleaning the building and helping with the administration. In Nueva Guinea the project also provided free meals, and a group of parents prepared these meals every day. Most of the parents who participated on the level of advocacy were part of the local board or helped this board. For example, they visited other parents to stimulate them to become a member of Los Pipitos, or talked at schools about the integration of children with a disability in regular education.

What is the influence of a. embedding in the community b. participation policy and c. amount of professionalization?

	Embedding in Community	Participation policy	Amount of professionalization
Basic communication	+	+	+ or -
Home improvement	+	+	+ or -
Volunteering	+	+	-
Advocacy	+	+	-

Table 4. overview of influence of embedding in the community, participation policy and amount of professionalization.

Community embedding

As table 4 shows, embedding in the community improved parent participation on all four the levels. It is notable that projects which received a lot of help from the community and/or did more to involve the community had a higher level of parent participation and more participation in the levels of volunteering and advocacy. In Nueva Guinea, San Rafael del Norte and León this was a fact. In San Rafael del Norte people of the community helped with transport to get members to important activities or meetings.

The participants mentioned that because of this help parents were able to participate. In León, where community embedding was very high, therapists and professionals worked voluntary in the center. Practical help made parent participation possible and improved the services offered by the project. Observations, focus groups and interviews showed that parents within the projects felt supported when receiving help from the community. Consequently, they were tented to participate.

The positive effect of community embedding was not notable in Potosí. In this project the community was willing to help, but hardly any parents or children were present; the project wasn't active. This illustrates that help offered by the community was not enough to increase parent participation. Observations showed that to create community embedding, the project and community have to work together.

Participation policy

Table 4 demonstrates that participation policy influenced parent participation in a positive direction. As stated in the project description, the general policy of Los Pipitos, used by every project, contains factors to enhance parent participation. But only when there was an active implementation of the policy in the form of activities in the projects the parent participation increased. Some boards organized meetings and working groups for the parents about their duties and rights as a member of the organization. In the projects where they did this on a regular basis parents turned out to be aware of their role and responsibility. The parents in the focus groups knew the regulations and explained that they were important for the sustainability of the projects. As some participants mentioned: "This board will go away one day and then other parents have to take it over".

Besides this, Nueva Guinea and San Rafael del Norte extended the parent participation policy by offering free meals and free transport. Results showed that this policy was successful, parent participation increased.

Amount of professionalization

The amount of professionalization, as showed in table 4, was influencing participation in both a positive and negative direction. The influence was mainly positive

for the participation in the therapies, since in the majority of the projects the professional therapists motivated the parents to participate. Furthermore, parents in the focus groups mentioned that the professional therapists were willing to listen to the parents and took the wishes of the parents into account when setting up the therapy plan. The parents felt taken seriously by the professional therapists and they were aware of the fact that they played an important role in the therapy of their children. In the majority of the projects therapists recognized and understood the important influence of parents in the therapy and that parents therefore should be involved. As one physiotherapist mentioned: "I am working one hour with the child, but the parent is at home with the child the other 23 hours and is therefore more important".

In Ocotal and Distrito VI parents were passive during the therapy of their children, only the professionals worked with the children. Observations showed that the mentality of the professionals was different in these projects; professionals were not trying to involve the parents during the therapy.

Professionalization on an organizational level turned out to be negative for the parent participation in Ocotal and Distrito VI. In these projects, paid professionals were responsible for the coordination and organization of the project. The parents in Distrito VI said: "She can organize activities and do all the work here, because she gets paid for it". This showed that parents at these locations did not feel a responsibility for the project. In Bluefields and Potosí professionals on a national level helped parents on an organizational level; they visited the projects occasionally. Observations showed that this support improved the skills of the participating parents. The professionals made clear that they were only supporting these parents, which was an important difference.

The amount of professionalization influenced the relation between parents and professionals. At the majority of the projects the relation between parents and professionals was informal and confidential; the therapy and advocacy part of the project were organized together. The approach of professionals made parents feel valuable as a member. For example in El Sauce, here a mother said: "We help because we know they take us in account". The equal relation was improving the feelings of self-efficacy and participation. In some projects like Ocotal and Distrito VI, parents came by appointments. In combination with the formal atmosphere in the projects and the professionals who not

explicitly tried to activate the parents, the relation was not equal. Parents lacked the idea that they were important for the project, what made feelings of self-efficacy and participation decrease.

Conclusion

This study focused on factors which contributed to the high level of parent participation in Los Pipitos, a parent organization for children with a disability in Nicaragua. The participation model of Shepard and Rose (1995) states that there are four levels of participation, which are related to the level of empowerment of the parent: basic communication, home improvement, volunteering and advocacy. This model was used in this study to structure the concept of parent participation. Interviews, observations and focus groups were conducted in eight projects of Los Pipitos between January and April 2012. The constitution and developmental plan of the organization were analyzed to set up these interviews. The results are structured in three themes; community embedding, participation policy and the role of professionals.

The amount and form of parent participation in Los Pipitos varied between different projects. The locations Nueva Guinea and Leon had a high level of participation, Ocotal, El Sauce and San Rafael del Norte an intermediate level. The amount of parent participation was extremely low in Potosí, Distrito VI and Bluefields. In every project, except Potosí, parents participated on the levels of communication and home improvement. Mainly in the projects with an intermediate or high level of participation parents participated in volunteering or advocacy.

Different factors inside the organization contributed to the level of parent participation. First of all, projects which were embedded in the community had more parent participation on the higher levels. Second, the policy of the organization contained factors which contributed to parent participation. Projects that adhered to this policy organized learning groups and recreational activities which stimulated the participation. Third, the role of professionals was ambiguous. In locations where professionals took over the role of the parent in therapy and organization the participation of parents diminished. Whereas in projects where professionals supported the parents, parent participation increased. This was seen in projects where professional therapists supported

the parents during the therapy of their child, and provided the parents with skills and exercises. In addition, national staff members supported parents of some projects with organizational skills and leadership trainings.

The reliability of the results may have been affected by socially desirable answers of the respondents. Socially desirable answers occurred because of several problems. First, because participants knew that the researchers visited Los Pipitos for the Liliane Foundation, second, the cultural difference between the researchers and participants and misunderstanding because of language difficulties had an influence. Finally, the answers can be affected by board members who were present during the focus groups.

The first problem was solved by explaining that the researchers were not from the Liliane foundation but only did a research for this organization. To overcome the cultural difference the researchers introduced themselves and explained their background. Additionally, they emphasized that there were no good or wrong answers and the interview started with easy questions. The researchers were still improving their knowledge of the Spanish language at time of the study. Therefore, some native speakers helped with the development of the topic list and the process of transcribing the interviews and focus groups. One interview was not used because of misunderstandings through language differences. The presence of a board-member during the focus groups could have influenced the answers of the parents, because some parents did not dare to be honest in presence of these persons. Since board members also made parents feel comfortable, and sometimes the board members helped with explaining questions and gave some extra information, this was not avoided.

When social desirable answers were detected, the use of different methods made comparison of the results possible. Overall, the answers did not differ much, but when results were inconsistent the researchers tried to check which result was correct. If this was not clear, those results were not used. For example, the information about the exact amount of parent participation in each project was not used because the information was not consistent. All these solutions improved the reliability of this study.

Discussion

As seen in this study the participation of parents in Los Pipitos is enhanced by community embedding and participation policy, but the influence of professionals is ambiguous. This influence of professionals can be explained by the participation model of Wolfendale (1985), which shows that parents and professionals share responsibility and are mutually accountable. In the projects where professionals took over the role of the parents, there is no mutual accountability between the parents and professionals and this explains why parent participation decreased.

According to other studies, (Hartas, 2008; Ketelaar et al., 1998; Trivette et al., 1996; Judge, 1997) parents' feelings of empowerment increase when they not only receive services but also have to contribute to these services. In this manner a sense of responsibility for a project or organization is developed. To make this possible the relationship between parents and professionals has to be equal. Professionals should take account of the experiences of the parent and combine these with their knowledge to create a therapy plan in cooperation with the parent.

Civic organizations must, therefore, be aware of the role of professionals in their organization. These organizations can develop an equal relationship between parents and professionals by, besides having professionals, training parents to volunteer in the organization. These trained parents share the knowledge and experience with parents without a training. Furthermore, they should make parents aware of their responsibility and tasks. Trained parents have an important role in this, again because they have the same experiences as the parents and know how to stimulate them. Moreover, to foster the equal role and responsibility of parents, they should be taken in account in the decision-making of the organization. Voting for leaders and annual assemblies help in this process.

Los Pipitos as an organization is founded with the idea of shared responsibility and this is the strength of the majority of the projects. In those projects where professionals are fully active, responsibility has to be divided between parents and professionals. Parents should be empowered to participate. Thus, workshops and learning groups for parents should be continued and expanded and empowering aspects in these workshops developed. Especially those workshops in leadership are essential to improve the participation of parents in higher levels. In addition, the general information

distribution about the role of parents in the organization should be improved, in a way that members and non-members alike are aware of the mission of Los Pipitos.

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Appendix 1

Témas entrevista investigación participación de padres Los Pipitos-2012

Universiteit Utrecht



Información

Numero de participante:

Nombre:

Edad:

Sexo:

Desde cuando active en Los Pipitos:

Lugar:

Proyecto:

Hijo en Los Pipitos:

Introduccion de entrevista

- Objetivo de investigación
- Duración de entrevista
- Discutir temas
- Uso de información de esta entrevista
- Explicar porque grabamos la entrevista
- (Encender grabadora)
- Explicar porque estamos juntos
- Garantizar anónimo
- Preguntas?
- (Controlar grabadora?)

- Que es su función en Los Pipitos?

Municipio

- Este capítulo esta situado en un lugar urbano o en el campo?
- Cuales son los condiciones de este municipio?
- Cuales son los condiciones de este municipio para niños con discapacidad?
- Cuales son los factores en este municipio que influyen positivamente el funcionamiento del capítulo?
- Cuales son los factores en este municipio que afectan negativamente el funcionamiento del capítulo?

Información general capítulo/CET/CRRET

- Este capítulo tiene un CET o un CRRET? Sí, desde cuando?
- Si haya un CET o CRRET, este capítulo CET/CRRET esta compartiendo un local o estan locales separados?
- Cuales servicios ofrece este capítulo?
 - terapias
 - educacion temprana
 - proyectos para jovenes, deporte, cultura
- Cuales actividades para padres ofrece este capítulo?
 - comisiones de trabajo (cual, quien, que)
 - grupos de apendizaje (GAF)? Cuales? Que pasa aquí?

Rehabilitativo

- cuantas y cuales tecnicas trabajan aquí?
- hay otras personas que reciben un salario aquí?
- de que manera padres participan durante la terapia de sus hijos?
- de que manera padres tienen una influencia durante la terapia de sus hijos? (proceso)
- de que manera la terapeuta toma en cuenta los deséos de los padres? (plan)
- Cual es la punto de vista de Los Pipitos sobre padres: Padres pueden ayudar en Los Pipitos con su propias experiencias o necesitan aprender la experiencia hasta que puedan ayudar?

(which is the vision on parents Los Pipitos has? Parents as persons with their own possibilities and qualities, which you are going to improve. Or parents as persons who don't know a thing and should be taught).

Asociativo

- Cuántos miembros de la JDM trabajan activamente en el capítulo?
- Cuántos reuniones tienela Junta Directiva Municipalpor mes?
- Cuando fueron los ultimos elecciones, cuantos padres se
- Cuántos afiliados tienen este capitulo?
- Cuales actividades realizan en su capítulo donde se tomen en cuenta a las familias?
- Hay comisiones de trabajo aquí? Cuales? Que hacen este comisiones?

- Quien empieza un commission de trabajo, y quien decide cuales actividades una commission va a organizer?
- Cuantas asambleas municipales realizan en el año?
- Cuantos padres estuvieron en el ultima assamblea municipal?
- Hay Redes de Amigos en este capitulo?
 - o Que hace un Red de Amigos?
- De que otras maneras hay en este capitulo para envolver la comunidad en este capitulo?

Preguntas mas específicas sobre participación de padres

-Cuantos padres estan participando aqui? Mas o menos?

Hay diferentes niveles de participación, comunicación principio, hacer terapia en la casa, trabajo de voluntario, participación en un nivel asociativo. En cuales niveles estan padres participando aqui?

- Cuales actividades realizan las padres aqui por nivel?
 - Padres tienen una influencia en un nivel asociativo?
 - >Sí, de que manera?

- Padres aqui van a reuniones en cuanto a proyectos, actividades?
- Usted podría describir la relacion entre los padres en este capítulo?

Policia de Los Pipitos

- Los Pipitos tiene algunos estatutos en cuanto a participación de padres:
 - Usted conoce estos estatutos sobre participación de padres?
- De que manera estos estatutos estan realizando en este capitulo? (La diferencia entre policia y la vivencia)
- Este capitulo hay niños del proyecto 'Liliane Fonds'? De que manera este capitulo esta trabajando conformelas reglas de 'Liliane Fonds' sobre participación de padres?
- Usted podría decir algo sobre la influencia de las reglas de Liliane Fonds al participacion de padres?

Observaciones

- Vemos ... podría decir mas sobre eso?

Appendix 2

Persona a un nivel de rehabilitación/consejero

Témas entrevista investigación participación de padres Los Pipitos-2012

Universiteit Utrecht



Información

Numero de participante:

Nombre:

Edad:

Sexo:

Desde cuando active en Los Pipitos:

Lugar:

Proyecto:

Hijo en Los Pipitos:

Introduccion de entrevista

- Objetivo de investigación
- Duración de entrevista
- Discutir temas
- Uso de información de esta entrevista
- Explicar porque grabamos la entrevista
- (Encender grabadora)
- Explicar porque estamos juntos
- Garantizar anónimo
- Preguntas?
- (Controlar grabadora?)

- Que es su función en Los Pipitos?

Municipio

- Este capítulo esta situado en un lugar urbano o en el campo?
- Cuales son las condiciones de este municipio?
- Cuales son las condiciones de este municipio para niños con discapacidad?
- Cuales son los factores en este municipio que influyen positivamente el funcionamiento

del

capítulo?

- Cuales son los factores en este municipio que afectan negativamente el funcionamiento del

capítulo?

Rehabilitativo

- Cuales servicios (activities) ofrece este capítulo?

- terapias
- educacion temprana
- proyectos para jovenes, deporte, cultura

- Cuales actividades para padres ofrece este capítulo?

- grupos de aprendizaje (GAF)? Cuales? Que pasa aquí?

- Cuantas y cuales tecnicas trabajan aquí?

- De que manera padres participan durante la terapia de sus hijos?

- Es lo mismo para todos los padres, o hay diferencias?

- Que hace la mayoria de padres durante una terapia?

- De que manera padres tienen una influencia a la terapia de sus hijos? (proceso)

- De que manera la terapeuta toma en cuenta los deseos de los padres? (plan)

- Cuantos padres realizan la terapia en su casa con sus hijos?

- Que usted cree que son las opiniones de padres sobre su rol en la rehabilitación de su hijo?

- Cual es la punto de vista de Los Pipitos sobre padres: Padres pueden ayudar Los Pipitos con

su propias experiencias o aun necesitan aprender la experiencia hasta que puedan ayudar?

(which vision on parents has Los Pipitos? Parents as persons with their own possibilities and qualities, which you are going to improve. Or parents as persons who don't know a thing and should be taught).

Preguntas mas específicas sobre participación de padres

Hay diferentes niveles de participación, comunicación principio, hacer terapia en la casa, trabajo de voluntario, participación en un nivel asociativo. En cuales niveles estan padres participando aquí?

- Cuales actividades realizan las padres aquí por nivel?

- Padres tienen una influencia en otras actividades de niños aquí?

> Si, de que manera?

- Padres tienen una influencia en un nivel asociativo?

> Si, de que manera?

- Que usted cree es la razon porque padres participan aquí?(Even kijken naar onafhankelijkheid).

Comparación de policía de Los Pipitos y la vivencia

- Los Pipitos tiene algunas estatutos en cuanto a los derechos y deberes de afiliados:
 - Usted tiene la idea que los padres conocen sus derechos y deberes?
 - Cuantos padres estuvieron en la ultima 'assamblea de afiliados'?
- Usted conoce los estatutos en cuanto a participacion de padres? De que manera estas reglas estan realizando en este capitulo? (La diferencia entre policia y la vivencia)

Observaciones

- Vemos ... podría decir mas sobre eso?

Appendix 3

Témas grupo focal investigación participación de padres Los Pipitos-2012

Universiteit Utrecht



Información

Capítulo:

Fecha:

Número de padres:

Distribución hombres/mujeres:

Introducción de entrevista

- Objetivo de investigación
- Duración de entrevista
- Discutir temas
- Uso de información de esta entrevista/anónimo
- Explicar porque grabamos la entrevista
- (Encender grabadora)
- Explicar porque estamos juntos
- Preguntas?
- (Controlar grabadora?)

Introducción

- Nombre, edad, cuando fue el primera vez usted vino a Los Pipitos? Cuales actividades usted hace en Los Pipitos?

Municipio

- Este capitulo esta situado en un lugar urbano o en el campo?
- Cuales son los condiciones de este municipio?
- Cuales son los condiciones de este municipio para niños con discapacidad?
- Cuales son los factores en este municipio que influyen positivamente el funcionamiento del capítulo?
- Cuales son los factores en este municipio que afectan negativamente el funcionamiento del capítulo?

Información general Capitulo/CET/CRRET

- Cuales servicios ofrece este capitulo?
 - terapias
 - educación temprana
 - proyectos para jóvenes, deporte, cultura
- Cuales actividades para padres ofrece este capitulo?
 - comisiones de trabajo (cual, quien, que)
 - **Grupos de Aprendizaje (GAF) Cuales? Que pasa aqui?**

Rehabilitativo

- Cuales actividades hacen los padres en este capítulo?

Pregunta mas sobre los profesionales que trabajan aqui

- De que manera padres participan durante la terapia de sus hijos?

Pregunta sobre la relacion entre padres y profesionales

- De que manera padres tienen una influencia en la terapia de sus hijos? (proceso)
- De que manera la terapeuta toma en cuenta los deseos de los padres? (plan)

Pausa

Asociativa

- Padres aqui van a reuniones sobre proyectos, actividades?
- Cuales padres reciben los estatutos de Los Pipitos? (traer librito)
- Cuales padres conocen los derechos y deberes de afiliados de Los Pipitos?
- Usted asistió un reunión alguna vez, donde se discuten los estatutos de Los Pipitos?
 - Que pasa aqui exactamente?

- Que pasa en un asamblea de afiliados? (*temas son cosas en cuenta al capitulo*)
- Padres tienen una influencia aquí en otras actividades a parte de terapia de sus niños?
 - > Si, de que manera?
- Quenecesitan padres para participar en (GAF's/Comisión de trabajo/JD)?
- Cual rol usted tiene en las decisiones en que se toman en el nivel del capitulo?
- Cual es la punto de vista de Los Pipitos sobre padres:Padres pueden ayudar Los Pipitos con su propias experiencias o aun necesitan aprender la experiencia hasta que puedan ayudar?

(which is the vision on parents Los Pipitos has? Parents as persons with their own possibilities and qualities, which you are going to improve. Or parents as persons who don't know a thing and should be taught).

Sentimiento de padres

- Porque usted esta involucrado en Los Pipitos?
- De que manera usted se siente involucrado en Los Pipitos?
- Cuáles son los beneficios como afiliado de Los Pipitos?
- Que usted cree es la razón para que padres participen en este capítulo?
- Podría contarme sobre situaciones logros del capitulo de los que usted esta especialmente orgulloso?

- Cuales considerará son las principales amenazas para el funcionamiento de este capitulo?
- Cuales considerará son las principales fortaleces para el funcionamiento de este capitulo?

Observaciones

- Vemos ... podría decir mas sobre eso?