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EMPOWERING THE POOR PARENTS OF CHILDREN WITH SPECIAL NEEDS

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Abstract— *Problem of children with special needs (CSN) in developing countries cannot be resolved completely if there is lack involvement of parents and the surrounding community. On the other hand, barriers to stigma and culture "ensnare" parents and the surrounding community to be involved in their care. The Foundation believes that even though poor parents of CSN suffered from double discrimination, they already had their own modalities, so they can help themselves. However, realizing that this mission was hard, cooperation was carried out with various parties. The foundation's vision is to support active participation through the role of parents and the community, so that the concept of community based rehabilitation and inclusive development is modified according to local culture. Analysis of content from FGDs, accompanionship with in-depth interviews, observation and field notes was examined to find out the supporting and inhibiting factors of a social organization for empowering the poor of CSN, hopefully it could be a lesson learned.*

Keywords—*children with special needs; poor; empowerment; parents*

1. Introduction

There were many definition of children with special needs (CSN), but the chosen term of CSN here were simple (means understandable) and should be included of the prevention and early detection of CSN to make people aware. So, CSN were referred to someone who are under 18 years old or more if their mental age are still under 18 years old - have growth and developmental problem and also need special services. 15% of the world‘s population are CSN, and make them as the largest minority group exist and 82% of CSN live in developing country with limited access (ILO, 2011). There is no accurate data of Indonesia ‘CSN, but it could be predicted 2 million CSN (SUPAS 2015). Fortunately, even with limited ability because of physical and mental intelligence impairment, CSN weren’t closed case. Their ability and potential could be explored and broadened with their parents’help as well as the acceptance from the society. However these ideal condition hadn’t achieved yet because most of the parents have difficulties in understanding CSN’s needs and potential. Empowerment of the CSN”s parents, especially the poor then become a task that have been prioritized so that CSN could be empowered as well.

Recently, even there were many government and private sector’ initiate an effort for CSN in Indonesia, regarding the ratification of Convention on the rights of Persons with Disabilities, but the discrimination in getting access especially in education was evident as only 36.4 % of CSN goes to school (SUPAS, 2015). Besides this, educating community and raise awareness of the CSN issue is a way to empower society in order to provide a better living place for CSN. This concept then formulated by World Health Organisation (WHO) as Community Based Rehabilitation (CBR), which making optimum use of local resources (WHO, 2011).

Peduli Kasih Foundation for CSN was founded on April 4th 2012 in Surabaya, Indonesia, with the vision in mind, tried

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to aid CSN's parents (especially the poor one) to accept, train and explore their CSN's potential and ability so they could active participating in the community. From the foundation belief, even though poor parents of CSN suffered from double discrimination, they already have their own modalities, so they can help themselves. So, in the beginning, our focus only to be as a parents support group, i.e the informal discussion to the parent of CSN about how to handle CSN in their house was frequently held. The parents could focus their attention to the topic of discussion, during the discussion, volunteer was taken care of their children in another room. Foundation also hope that this service could be as a respite care for the poor parents of CSN. As for most the poor parents could not afford to pay a servant who take care of their children and nobody could be as a caregiver to the CSN except the mother herself, actually parents were suggested not to bring their CSN. Instead of play and learn programme for CSN, the art and sport child class were provided during their parents class.

Considering that there were many obstacles that parents could not joint this service, like language barriers, transportation obstacles or underestimate mindset (Flores, 2006). So, after internal evaluation, thinking of the prioritation service activity gave to the nearest subdistrict. It means, the level of engagement between the foundation and parents could be better, in order to get easier way for regularly home of CSN visit and make better relationship with certain decision maker and stakeholder related to CSN.

Based on this approach, the foundation service approach is not as a therapy center or school for CSN, but on the empowerment of the poor parents CSN and CBR. To accomplish these doing good job, all of the service were free of charge. These facts made to determine how the foundation empowering the poor parents of CSN without no fee ?

2. Method

Qualitative and action research were conducted to be chosen, in order to have enriched data of the empowering the poor access of CSN. At first, collaboration with many parties should be caught. All of the resources, like the offering from the university student programme as they need the field project to be done as a volunteer, even we also discuss with their lecturer as a coordinator and supervisory. Secondly, collaboration with the head of subdistrict and significant other key formal and informal leader as their voice could be as reinforcing factor to be success programme.

After coordination with all of the parties, the project consist of focus group discussion with the head of subdistrict public service office and accompanionship with the selected poor parents of CSN which was followed by in depth interview, observation and field notes.

Step of conducting the research:

- Preliminary study: 4 staff of the foundation who graduates from psychology and communication studies did 6 focus group discussion for 2 consecutive days. After the analysing these FGD preliminary data, was continued by 17 indepth interview to active parents member of foundation to select the parents who had commitment to their CSN. 7 parents' CSN were selected to get scholarship for optimalize the CSN potency.
- Volunteer training and supervisory: 15 psychology students was involuntary jointed the training and then selected to become 7 research assistent. Topic of the training : CSN and their problem, volunter task and role, practice as a facilitator of CSN as an introduction of research assistant.
- Assesment of the CSN and their parents' condition: 2 psycholog and 1 doctor assess the commitment of the parents' CSN and constructed the Individual Education Plan (IEP) for each of the selected CSN.
- Accompanionship and reporting of the data: CSN home visit every week by the certain volunteer to interview and observe the family of CSN then the verbatim and field notes instrument were filled.
- Analysing of the data: all of the qualitative data were analysed and categorisation to the findings criteria.

Table 1: Demographic data of the informan

	Types of informan	**Criteria of Sex**		
		Men	Women	
1	Formal leader	8	18	
2	Informal leader	12	36	
3	Member of family of poor CSN	12	17	
		Criteria of age		
		Younger (under 40 y.o)	Middle (40-55 y.o)	Older (55 y.o and above)
1	Formal leader	6	14	6
2	Informal leader	8	18	22
3	Member of family of poor CSN	4	20	5
		Criteria of education level		
		Graduation of basic level	Graduation of middle level	Bachelor and beyond
1	Formal leader	0	4	22
2	Informal leader	12	26	8
3	Member of family of poor CSN	6	18	5

Findings: empowering of poor CSN could be categorised through the holistic effort:

- Encompass the formal and informal leader opinion as the structural aspect to look for the local cultural and values and through informal discussion and trustable relationship.
- Collaboration with many parties, not only with university lecturer and practician (psycholog and doctor), but also the decision maker, cadre, field public figure and student as volunteer.
- Accompanionship and be friendly communication for all of the aspect

The supporting factor to empowering the poor CSN without fee depend on:

- Collaboration of all aspect in the community, moreover the formal leader
- Sincere relationship in between all participants

The inhibiting factor to empowering the poor CSN without fee depend on:

- Barrier to communication regarding perceptions of underestimate mindset
- Lack of commitment from parents and decision maker

As a foundation that have run for nearly 7 years, we figured out the way of parents cooperation and involvement was through empowering of poor CSN. With a proper engagement, parents were more motivated to do better and applying their knowledge to full potential. Hibbard and Greene (2013) also stated that parents' engagement would optimalize the chance on better result on the CSN potency. The most important part on the said engagement was active participation in the process of deciding the procedure of home exercise that will be taken (Guadagnoli and Ward, 1998). Carman (2013) had conceptualize the framework of parents' engagement using three level of engagement, i.e.: direct care, organisational's design and policy making.

Carman's framework on parents' engagement displayed the continuation of direct care as a process of deeper involvement. This level integrates patient's values, context and perspective that would be used to manage CSN condition including exercise preference.

When the engagement evolved deeper, parents will share leadership and same rights to decide the exercise procedure based on parents and CSN preferences and judgement. Parents reluctance to actively participate were affected their individual characteristics and the contextual dynamics, such as education, social background, knowledge, language, culture and values (Blumenthal-Barby, 2017). These characteristics differ and affected parents' willingness in their involvement and engagement. The contextual dynamics were not only about scheduling, it is also about the interaction between CSN - parents, family and community, as well as the clash of the individual characteristics.

Community have high awareness on CSN but they have minimal information about CSN both in general and special information, and also how to interact with CSN as a live experiences. Community have sympathy to the CSN but they are confusing how to interact or cannot imagine if they were having CSN. Their psychomotor were passive, because they were afraid to make hurt of parents. In other side, the initiation of CBR was still confusing, which was better initiated, by internally or externally. Moreover, the most important to do CBR is the sustainability and to do this it need the engagement and rapport to be built before and during the initiation. The shared value is the big hurdle that have to be passed by any organisation doing CBR (Macionis, 2008).

To make sustained of the empowering poor CSN programme, it need trust, frequent and informal discussion. The provision of volunteer willing to help by unpaid was important, but because of self-motivation that was different in each person. So satisfy the volunteer is important by understanding and communicating and network and experience. Driven by self-motivation, volunteer is potential resource to build engagement with internally, like the key informal leader at the same time.

3. Conclusion

Empowering the poor parents of CSN without fee should be provided in collaboration with many parties, such as formal and informal leader, based on local cultural, and covered by individual (parents)'needs through informal discussion, frequent and trust. This experiences could be as lessons learned for poor CSN Surabaya empowering community.

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