MOLISA

Qualitative Research

CHILDREN WITH DISABILITY IN AN GIANG AND DONG NAI

KNOWLEDGE – ATTITUDE – PRACTICE

Report for UNICEF Viet Nam

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ABBREVIATIONS

Abbreviations	**Explanations**
BCC	Behavioral Change Communication
CBR	Community – Based Rehabilitation
CWD	Children with Disability
FGD	Focus Group Discussion
IDI	In-Depth Interviews
IEC	Information – Education – Communication
KAP	Knowledge – Attitude – Practice
NGO	Non-Governmental Organization
PWD	People with Disability
Q&A	Question and Answer
UNICEF	United Nations Children’s Fund

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I. EXECUTIVE SUMMARY

This qualitative KAP study is intended to provide evidence for advocacy and raising public awareness on Children with disability (CWD) in An Giang and Dong Nai provinces and nationwide. The main objectives of the study are:

1. Analyze the overall situation on knowledge, attitudes, and practices towards CWD of people in Dong Nai and An Giang provinces;
2. Conduct the communication analysis in the two provinces including: communication capacity analysis, communication channels, availability of materials, audience analysis on CWD;
3. Propose recommendations for the further development of a communication strategy and social support systems on CWD in Viet Nam.

The research team used qualitative research methods (focus groups, in-depth interviews, and home-based observations) to collect needed data with different types of audience at three levels: province, district, and commune. Primary study participants included CWD; non-disabled children at inclusive schools; parents with CWD; parents of non-disabled children; special and inclusive school teachers; provincial, district and commune leaders in charge of children and social protection issues and members of women`s union. The research team conducted a total of 24 FGs, 21 IDIs, 6 home visits, and 3 case studies during the period from July 29th to August 5th in An Giang and Dong Nai. Primary study sites were at Dinh Quan district (Dong Nai) and Phu Tan district (An Giang).

1.1. Main findings and conclusion

Knowledge:

Knowledge on concept, causes, and classification of CWD was poor and reflective of the audience's experience or imagination on CWD rather than their acquired learning. The knowledge on disabilities prevention, early detection and interventions was limited among adult participants.

Attitudes:

Parents generally accept their CWD as disadvantaged members of their family and thus tend to give them more emotional support and care relative to other kids. This finding was more obvious in families with home-based care takers and better economic conditions. Community or school members (including teachers and non-disabled pupils) generally hold supportive attitudes towards CWD (mostly emotional, and partly materialistic). But stigma and discrimination also exists to a lesser extent (verbal and action), especially between non-disabled children and CWD. Sometimes, stigma and discrimination led to self-stigma among a small portion of CWD. Unfortunately, this problem goes unnoticed by adults including parents, teachers, and local authorities. Support from local authorities was minor (through home visits, advocacy for donation, and policy implementation) and not systematic throughout the study sites. These types of support co-exist in some communes but not in others, leaving many severe CWD vulnerable.

Health care:

CWD in the study sites did not receive adequate health care and rehabilitation services, but received better care regarding home-care and hygiene from their family members. Lack of knowledge and skills on prevention of diseases for CWD; lack of confidence in rehabilitation success; far distance from household to health care facilities; and especially poverty were major family-based barriers for CWD health care and rehabilitation. At the same time, challenges and difficulties within the health system largely prevented CWD from receiving timely and quality health care and rehabilitation.

These challenges included shortage of early disabilities preventive and diagnostic services; absence of effective health care counseling services and village health workers and collaborators overloaded with multiple tasks. Both hospital-based (in both provinces) and community-based rehabilitation (Dong Nai only) faced various challenges: shortage of infrastructure, equipment/tools, and staff; ineffective technical transferring from hospital to communities; lack of technical support from rehabilitation staff to parents; and lack of incentives for rehabilitation collaborators at grassroots levels.

Education:

Despite the co-existence of the three sub-education systems (inclusive, exclusive and social protection facilities), many barriers restricted the accessibility of CWD to quality education. The most disadvantaged groups include children with severe mobility disabilities, behavioral disorders, and intellectual disabilities. Major barriers at individual and family levels included the severity of the disabilities and health conditions; parents' pertinent worries that their kids would suffer at school; unawareness of education opportunities and the rights for CWD; lack of confidence in CWD' ability to learn; far home-school commuting distance; and poverty and parents' interest in earning their living. At institutional and community level, major barriers include the absence of education counseling; lack of collaboration between local authorities, mass organizations, and education sector in promoting education; lack of mechanism to support policy and law implementation; and particularly prevailing child labor (including labor of CWD).

Communication:

Village and commune personnel are the primary and preferred communication channel for parental education. Books and newspapers are the preferred channels for CWD who currently go to school (as they could access these materials at school) whereas TV and radios are the most common channels for out-of-school CWD to receive information. Local radio systems were functioning but much less interesting than TV and national radio programmes and thus did not get attention from parents and CWD. Communication capacity, especially at community level, is limited in general due to lack of interaction between communicators (i.e., staff, teachers) and audience (parents, CWD); absence of communication materials such as leaflets and booklets on CWD; and an absence of standardized sign languages used on various national TV channels such as O2 TV.

Entertainment and public services:

Overall, CWD had limited access to entertainment and public services, especially those with severe movement and visual disabilities, and behavioral disorders. Common entertainment activities for CWD include jumping ropes, soccer, and ball-rolling games (both at school and in communities). Most public services in the two provinces did not have any construction features tailored to people with disabilities except a central park in An Giang and a ticket-free bus for CWD in Dong Nai.

Vocational training and job opportunities:

Both provinces face difficulties in implementing vocational training and seeking job opportunities for CWD. Barriers for vocational training include a limited number of vocational training facilities; lack of teachers specialized in CWD; far distance from home to training facilities; health conditions of CWD; and poverty. At the same time, job opportunities are restricted by various factors which include unstable job markets; and incompatibility between supplies and demands (taking into account the timeliness of an opportunity, educational level of CWD and distance from home to factories).

Values and life skills:

CWD respect their surrounding networks and relationships, particularly those with their close friends, parents, and neighbors. Still, they tend to suppress their negative feelings and sorrow that other people brought them and generally hesitate to express their demand or request from others to assist them. CWD particularly lack communication and conflict resolution skills, especially when they were bullied or discriminated by others.

Collaboration among stakeholders:

At present CWD-related activities are integrated into general child-care programmes and those agencies (especially education, social protection, and health sectors) implementing the rights for CWD work independently from one another and not under a united coordination. There was an insufficient inter-disciplinary collaboration (particularly among health, education and social protection sectors) on surveillance and supervision in ensuring the rights for CWD. This lack of collaboration led to unsystematic and inaccurate databases on CWD in the two provinces.

1.2. Key recommendations

POLICY MAKERS

1. Strengthen the database on CWD through enhancing collaboration among key stakeholders in the surveillance system.
2. Strengthen the roles of the health care system in counseling and communication activities through integrating a component to educate the community.
3. Increase the coverage and technical support for community-based rehabilitation through establishing or strengthening the CBR for An Giang & Dong Nai.
4. Transfer rehabilitation techniques for family while reinforcing supportive supervision at households through training grassroots rehabilitation collaborators.

HEALTH CARE PROVIDERS

5. Health care professionals directly implementing national health programs/campaigns or working at public health facilities should be provided counseling skills and enough information about the rights and opportunities for CWD in the province and nationwide.

SCHOOL ADMINISTRATORS AND TEACHERS

6. Inclusive schools should be equipped with or take appropriate actions on inclusive teaching manuals and materials; Rehabilitation tools and sport tools for CWD; Organize extra sessions for CWD and pay commission for the teachers who teach such sessions; Set up friend-help-friend models of cooperative friends (like friend circles): Make more effort to establish stronger relationships with families in making cooperative plans to teach CWD at home and at school
7. Exclusive schools should standardize the entrance assessment, lesson plans and skills to cope with different types of disabilities; Reinforce technical supports from seniors and from higher level; Extend counseling services on early intervention to the community; Give CWD more opportunities to take part in the outside environments.
8. Social protection centers should have plans to improve the skills of caring and teaching CWD for their staff.

LOCAL AUTHORITIES

At commune and village levels:

9. Review the list of policy beneficiaries and readjust the policy implementation at each village and commune for neglected CWD.
10. Support families with CWD in preparing them for schools or encouraging continuing education.
11. Increase accessibility of CWD to entertainment services through diversifying recreational activities and exercises suitable for different types of disabilities of children.

At provincial level:

12. Standardize existing social protection centers, targeting the integration of nurturing, rehabilitation and teaching life skills for CWD.
13. Mobilize internal resources from vocational guidance and training system through evaluating capacity of local vocational training systems and employment opportunities for CWD.
14. The vocational training activities for CWD should be included in the general development strategy of the province.
15. Integrate mainstreaming CWD into government programs and projects.

GRASSROOTS COLLABORATORS

16. Health care collaborators at grassroots level should be equipped with effective communication skills (for behavioral change communication) and time/work management skills.

PARENTS AND CARE-TAKERS

Health care and rehabilitation

17. Increase knowledge, enhance skills and create belief of parents and care takers in taking health care of and rehabilitation for CWD.
18. Promote practices among parents and care takers to ensure quality healthcare and rehabilitation for CWD.
19. Instruct parents/care takers on making rehabilitation tools from existing cheap materials and on time management.

Education

20. Raise awareness among parents and care takers of education opportunities and the need for education.
21. Establish a model of caring among families with CWD.

CHILDREN WITH DISABILITIES

22. CWD must be equipped with social skills like assertive communication including expressing their demands and concerns. Training courses should use some models of successful CWD from which CWD analyze the reasons for success.

GENERAL PUBLIC

23. Establish social norms in treating CWD such as media programs that focus on building positive images of CWD.
24. Increase multi-sector cooperation and collaboration in implementing the rights of CWD.

COMMUNICATION CHANNELS AND STRATEGIES

25. Communication channels should be tailored to different target audiences.
26. Communication programs should capitalize on the existing knowledge, skills, belief, and practices of different targeted audience and reconstruct them based on the newly-effective law on CWD.
27. It is essential to develop communication materials such as leaflets, booklets with pictures and attractive illustrations, and technical manuals. Communication through small groups, using pictures, dramas, problem-solving are effective ways which people can use to enhance their communication effectively.

II. INTRODUCTION

Since 2008, UNICEF Viet Nam has implemented a cross-sector programme (health care, education, water and sanitation, child protection, social policy and planning) for Children with disability (CWD) including victims of Agent Orange in Viet Nam. The programme implementation is based on an existing mechanism of UNICEF supported work and partnerships to strengthen policies, legislation and programmes for CWD and their families. To implement the programme UNICEF adopted a multi-sector, rights-based approach and is guided by the Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of People with Disabilities (PWD). Thus, CWD are seen within the broader context of children's rights.

The programme includes both national and sub-national components. At the national level, the focus is on the policy/legal framework and some situation analysis and data-related activities. Sub-nationally, the programme focuses on capacity development, advocacy, service delivery and research in the three selected provinces: Da Nang, Dong Nai, and An Giang. At sub-national levels, the programme also aims to raise the awareness for key stakeholders on the rights and needs of CWD. Therefore a strong communication component is being developed to ensure various actors, starting with the children themselves, will have access to relevant information and skills. In addition, an effective advocacy campaign targeting policy and decision makers and the mass public will be implemented simultaneously to ensure a conducive and enabling environment for all programme interventions.

Furthermore, communication interventions supported by UNICEF will be planned for different groups of audience. Nationally, the focus will be on raising awareness on the Convention on Persons with Disabilities. At the community level, advocacy and communication activities will focus on changing negative attitudes and beliefs towards CWD. The development of a specific advocacy strategy will be a key step.

In order to develop a comprehensive communication strategy, a Knowledge, Attitudes and Practice (KAP) study is essential to understand the current situation, as well as the level of understanding and awareness of key governmental, non-governmental actors and target population of issues related to CWD. The analysis, conclusions and recommendations of the KAP study will help better to design and develop programmes and social services and activities. In addition, the results of the KAP study will serve as baseline information for UNICEF supported project interventions and activities, especially behaviour change communication (BCC) towards CWD.

In 2009, a CWD KAP study was conducted in Da Nang by the Taylor Nelson Sofres (TNS) Pte Ltd with financial and technical support by UNICEF. The CWD KAP study in Da Nang was held in seven districts, applied both quantitative and qualitative methodologies. The results show both advantages and challenges remaining in CWD KAP in Da Nang. For example, over 90% of respondents mentioned that they do respect children with disability and their families and believe that disabilities can happen to anyone. About 85% of them believe that children with disability depend on others most of the time and 73% think that children with disability are treated well by the Vietnamese society. However, 60% consider that children with disability are a burden for their families and/or for the society; and that they come more from poor families. Recommendations on suitable communication channels are raised in the report. This data provides crucial information for designing a CWD communication strategy in Da Nang in particular and will contribute to the development of advocacy strategy at the national level.

In 2009, UNICEF expanded its' disabilities related activities in An Giang and Dong Nai provinces. However, there is very little background information and data on the situation of CWD in these two provinces. In the 2009 AWP it is planned to conduct similar studies. As the general figures regarding people's KAP are already provided in the quantitative analysis in the KAP study in Da Nang, in order to save resources and time, and to avoid the duplication of work, the KAP study in Dong Nai and An Giang will focus on qualitative analysis. The CWD KAP will use qualitative tools to analyze socio-

Household visit in An Giang province

cultural factors, pros and cons that influence people behaviours toward CWD. The KAP will conduct a behavioural analysis to understand the willingness, belief, and issues that can trigger changes for CWD and their caregivers.

The main purpose of conducting a qualitative CWD KAP study in Dong Nai and An Giang is to provide information and communication analysis to develop and implement an evidence-based and comprehensive communication plan for advocacy and raising public awareness on CWD in the two provinces. Together with the CWD KAP study conducted in Da Nang, this will contribute to the development and implementation of a comprehensive communication strategy at the national level.

The main objectives are as follows:

- Analyze the overall situation on knowledge, attitudes, and practices towards CWD of people in Dong Nai and An Giang provinces;
- Conduct the communication analysis in the two provinces including: communication capacity analysis, communication channels, availability of materials, audience analysis on CWD;
- Propose recommendations for the further development and enhancement of a communication strategy, and of the social-supporting networks for CWD in Viet Nam.

III. BACKGROUND

This section is intended to provide an overall background on situations of CWD in Viet Nam. Basically, it summarizes the major findings from desk-research on different aspects of CWD and has four main components:

1. Distribution of CWD in Viet Nam: this component provides some statistics about CWD in the country.
2. Major issues of CWD: this component discusses the major issues that CWD and their families have been facing. These include accessibility to education services; health care and rehabilitation services; information; public and entertainment facilities; and employment.
3. Contexts around the issues. This component discusses contexts or determinants underlying each and both of the above CWD-related issues. The contexts include: family contexts; institutional contexts (especially health and education); social and community contexts; and policy and law implementation status.
4. Some insights on CWD-helping strategies: this component discusses some strategies that carry some features that promise success in ensuring the rights for CWD.

3.1. Distribution of CWD

While there was no systematic data on CWD, the number of this sub-population in Viet Nam was estimated to be around 1 million [1, 2]. According to a survey by MOLISA in 1998-1999, most CWD had multiple disabilities (an average of 1,5 forms of disabilities per CWD) [3]. Mobility impairment was the most common type, followed by hearing and speech impairment and intellectual retardation [1, 3, 4].

3.2. Major issues

Access to education services

Overall, despite the effort in promoting education for CWD over the last two decades, inadequate access to education remained a critical issue for this population in Viet Nam. According to MOLISA (1999), only 40-50% of children with disability received education through both inclusive and special education forms [5] whereas MOET reported about 25% of the one million Vietnamese children with disability were attending school [7].

Findings of research and studies on illiteracy among CWD were not systematic, but actually raised a big concern about inadequate education for CWD. Some research reported that one in every four People With Disabilities (PWD) was illiterate and that PWD who were illiterate and who had not yet finished elementary school accounted for around two-thirds [4]. Illiterate CWD alone accounted for about one-third[8]. A community-based survey reported an even higher proportion of illiterate CWD (aged 6-17) (45,5%) [3].

There was a division in the quality of education for different types of disabilities and for urban-rural-mountainous residency. Specifically, children with mobility impairment were more educated than those with other types of disabilities, especially with hearing, visual, and intellectual impairments [4]. At the same time, urban CWD were more educated than rural and mountainous CWD. In addition to other types of education, home-based tutoring or home schooling, contributed largely to the advance of urban CWD.[5]

A typical house painted by children with disability in both provinces

Non-school enrolment and dropout were also common among CWD. According to some research, around 20% of CWD from 6-18 years dropped out of school or never went to school.[3, 9] Impaired health conditions, and limited intellectual capacity were main reasons for this drawback.[9]

Access to health care and rehabilitation services

Health care and rehabilitation services were not highly available and accessible to CWD. Research suggested only a small portion (around 10%) of CWD actually received treatment or medical interventions such as surgery or prosthetic assistance[10]. In some research, up to one-third of all CWD living in households never sought treatment for their disabilities and only one-fifth of CWD used rehabilitative aids and devices, which is fairly low considering about half of CWD have severe disabilities.[3] The vast majority of rehabilitative devices being used were purchased rather than received through donation.[3]

The limited access to health care was more critical in rural areas. For instance, one study showed while 90 percent of CWD living in urban areas of the Red River Delta region sought treatment, only 29 percent of CWD living in rural areas of the Central Highlands did so.[3]

Access to information

PWD and CWD had limited access to information due to the lack of built-in features or communication programs tailored to their disabilities. Consequently, PWD and their families were not fully aware of their own rights and the benefits available to them, and particularly of available services intended for them.[10] For example, only 1% of PWD in a study knew about associations of disabled people [10], or few CWD living in their households were aware of rehabilitative services. [3]

The following section summarizes some findings from recent research on accessibility of PWD to different communication channels.

Televisions seemed to be the most interesting media to PWD[11], but it was not tailored to PWD. A content analysis research in 2009 found that no special TV program was available for PWD and no TV programs had any built-in features intended for PWD. No sign language or subtitles for people with hearing impairment were available in any of the TV programs.[12]

Newspapers, a primary print communication media, commonly provided a limited amount of information on PWD. Literature documented 146 newspapers and 251 journals in Viet Nam, but none of these specialized in PWD. Some newspapers conveyed contents about PWD but in limited amounts, often integrated in some news columns of certain newspapers.[12]

On-line Newspapers/ Websites, while not yet becoming widely available to PWD, were most reflective of PWD' interests and demands of information. Some websites conveyed news, forums and information for PWD and were regularly updated (http://www.pwd.vn, http://hoikhuyettatvt.org and http://www.nguoikhuyettat.org). Some websites even provided training such as IT for PWD and shared information about job opportunities and connections with donors (http://www.nguoikhuyettat.com and http://www.nghilucsong.net). Interestingly, all of those websites were managed by PWD in collaboration with non-disabled people.[12] However, these websites were not easily accessible to all the PWD as they did not have the sound version for the people with visual impairments. Neither were there user-friendly versions for people with physical disabilities. [12] Another website enlisted a large resource for PWD.

IEC materials such as leaflets, booklets, and manuals were also available for PWD and their families but were restricted to some projects or piloted programs. Samples of such materials included booklets on prevention, early intervention, community-based rehabilitation, and so on. [11] Most of these materials were often produced through NGOs' support, and mostly channeled within restricted settings such as special schools or project-assisted community settings[13]. In Da Nang, for instance, such materials were mainly delivered through the three special schools for CWD: Thanh Tam school (mainly for Children with Intellectual Disabilities), Nguyen Dinh Chieu School (mainly For Children with Hearing Impairment) and Tuong Lai School (mainly for Visual Impairment). This restricted distribution allowed only a small portion of CWD and their families to access such helpful materials.[11] Probably, because of that distribution mechanism, special schools served as a trusted resource for parents and family of CWD, but they were often limited in numbers and sparsely located, thus limiting the accessibility.[12]

Other communication tools for PWD such as Braille letter boards, cassette tapes, sign language, and hearing-aids are still limited and expensive. Furthermore, PWD have very few opportunities to gain exposure to mass media in general. [12]

Access to public and entertainment facilities

Most public infrastructure facilities were not easily accessible to, or used by CWD. Offices, residential buildings, roads, park and public toilets were not convenient or safe for them, and thus restricted them from fully utilising such services[5]. Difficult access to public transport was the most concerning. In some research, CWD's parents expressed their serious concern about the poor accessibility to public transport and highlighted it as a major obstacle to integrating their CWD into the community. [11]

Little is known about CWD access to entertainment services, but this type of access seemed restricted, especially for those with visual, behavioral, and intellectual impairments.

Access to employment

Unemployment and low-income among PWD raises concern about preparing vocational training and job opportunities for CWD in the future. According to some reports, only over 15 per cent of PWD of working age had suitable jobs with a stable income[14]. Literature suggested that impaired health conditions and insufficient job skills were primary causes of unemployment or self-employment among PWD[4, 10]. Low-income was noted as a pertinent challenge even for working PWD. [10]

In addition vocational training was not widely available, or easily accessible, to PWD. Limited services[3], high costs, inconvenient distance, and perceived absence of job opportunities were major barriers for PWD to seek vocational training.[10]

3.3. Context around the issues

Family context

Acceptance and actions to help CWD

Over time parents of CWD tended to accept their child's situation and wanted to do something to help their children rather than living in denial. Instead of feeling guilty about the child's condition, they saw taking care of the child as a responsibility and a necessity[11]. This positive shift helped form a more intimate bond between parents and CWD. Although research suggested that institutionalized CWD were at risk of staying there for life[8], they remained in regular contact with their families. A recent survey reported that most of the institutionalized CWD had weekly contact with family members. However, the family bond seemed much looser for children with behavioral disabilities.

In the same study around one-third of institutionalized children with behavioral problems reported having no contact with family members.[3]

While parents increasingly accepted their child's condition, many held a pertinent perception that their child was inferior and disadvantaged compared to other non-disable children of the same age[11]. This attitude unnecessarily prevented them from taking the child to schools and other social activities (including cultural and social events).

More concrete and positive actions were commonly seen in wealthier families. With financial advantages, these families could access more services such as information, health care, and particularly rehabilitative services and devices.[11] Unfortunately, such services were commonly costly and out of reach for poor families.

CWD family awareness of available services and benefits

Parents of CWD were generally lacking accurate information about the condition their CWD health, and services available to help them. Health and rehabilitation services might be available, but no system existed to communicate effectively with parents about such services. Consequently, parents were left ignorant about the causes of disabilities, types of disabilities, early detection, diagnosis, necessary health care, support or strategies to take care of their children[11]. Ironically coaching for families of CWD was available regarding early intervention, inclusive education, rehabilitation, and home-based care, but only a small portion of parents with CWD attended such events [11].

Parents were also short of information about the availability and benefits of inclusive education. For this reason many parents doubted that this education would benefit their child. This perception was more obvious for families with visually-, intellectually-, and behaviorally-impaired children. This lack of awareness and knowledge on the importance of inclusive education versus special school/ institutionalization sometimes caused them to keep their children at home, or to send them to a special school (special education).[11]

Little is known about parents' awareness of the rights of CWD. According to some research, they were not even aware of all the types of disabilities, let alone the rights for CWD.[11]

Financial capacity

Financial shortage was a critical challenge for families of CWD. Research has shown that financial capacity was a decisive factor for those families seeking rehabilitative aids, health care, education, and other services for their CWD. According to some research, only wealthy families could afford such services, leaving them almost out of reach of poor or low-income families.[5, 11]

Given the great majority of families with CWD were in need of financial support,[11] only a small portion of this population accessed this support. According to some research, the proportion of CWD living in households receiving some financial support was only 5 percent in urban areas and 10% in rural areas.[3]

Peer network

Self-help groups among parents to share information about CWD's care existed in different parts of Viet Nam. But the absence of legal status, lack of facilitation and coordination skills restricted this type of organization to independent and separate units. They did not have significant collaboration and networks to empower themselves and to develop into professional and sustainable entities.[8]

Institutional and supplying contexts (supportive strategies)

Education services

Viet Nam has deployed three types of education for CWD: inclusive, semi-inclusive, and special education. While inclusive education has been recommended as the most important strategy to integrate CWD into mainstream society, the last two forms still prevailed[8]. Literature also noted that inclusive education was more appropriate for children with movement/hearing and speech/visual disabilities, whereas special education was more appropriate for children with intellectual disabilities. For both of these education forms, pre-integration classes take place at kindergartens in order to help children with disability catch up with their peers in primary school. [5]

Much discussion has taken place about the challenges regarding inclusive education. Lack of special facilities for CWD such as toys for intellectual development, digital hearing aids, and sound-proof rooms, etc. and unsuitable buildings, were primary challenges.[11] In addition teachers were actually discouraged from pursuing the task of incorporating CDWs into inclusive education for the following reasons: inadequate training and preparation for teachers; the lack of adapted curriculum; lack of incentives for teacher contribution and responsibility to include CWD in their classes. [8, 11]

Community members held different positive and negative opinions about inclusive education which, to some extent, affected accessibility of CWD to this type of education. While they generally valued the benefits of inclusive education for CWD, many were doubtful about the impact of this education on the children’s intellectual and behavioral impairment. Some research suggested that about half of the community members did not want such children to receive inclusive education [11].

Special schools were available but often oversubscribed. For example, Da Nang had only three special schools (Tuong Lai, Nguyen Dinh Chieu, and Thanh Tam) but all of them were oversubscribed [11]. It was estimated that only around 2% of the total number of children who could benefit from such educational opportunities did so.[1, 5]

Much research suggested that institution-based education was not ideal for CWD because of the absence of opportunities to integrate them into mainstream society. Despite the fact that institutionalized CWD might like staying there because of the kindness and sympathy of staff and the opportunities to make friends[3], research raised the concern that they risked staying there for a long time (5-12 years), even for life. [8]. Many of them found it hard to stay away from home as they missed parents, were bullied by other friends, or even poorly treated by staff[3]. A serious concern is that children generally entered institutions not because they fulfilled the actual needs of CWD, but because their families had limited resources to provide food, education and medical care.

Furthermore, once institutionalized, the child remained there without periodic review or needs assessment for readjustment or further rehabilitative and care alternatives. The absence of a clear mechanism for families of CWD to seek services; a limited identification and assessment programs for at-risk families; lack of trained staff at institutions; and no system of monitoring or periodic review for children in alternative care contributed to prolonged institutionalization. [8]

Health care and rehabilitation services

The health sector has had a shortage of early prevention, identification and early intervention of disabilities at various levels, particularly at district and commune levels. This shortage might have contributed to plethora of CWD as research has documented families having several CWD whose disabilities could be prevented through medical genetic counseling or a new-born screening. [11]

Various forms of rehabilitation services were available for different types of disabilities, but did not meet actual demands of CWD. The services existed in three forms: institution-based rehabilitation, outreach rehabilitation, and community-based rehabilitation, but all confronted barriers in reaching

CWD. High costs and inconvenient distances restricted the institution-based rehabilitation (commonly in hospitals) to only a small portion of disabled people[5] who were generally more knowledgeable and wealthier[11]. Outreach rehabilitation was limited due to its deployment in remote areas and often with assistance from foreign operators [5].

Community-based rehabilitation (CBR), the most popular form, was initiated in the early 1990s and largely adopted by most provinces, but this service was generally insufficient both in numbers and in quality [8]. Inadequate funding, poor implementation, limited expansion, and lack of maintenance contributed to the lack of services [8]. Furthermore, inadequate training on rehabilitation, and absence of incentive prevented rehabilitation staff from working effectively with families of CWD[8]. This situation prevented many CWD from receiving the service. Even among the recipients, only a small number received rehabilitative aids such as prosthetics, orthotics, hearing and vision aids, or wheelchairs.[8].

Rehabilitation services were also limited in Dong Nai and An Giang. In Dong Nai, both in-patient (hospital-based) and community-based rehabilitation services existed but they lacked equipment and facilities for CWD. The in-patient centers just provided post-surgery rehabilitation in the provincial pediatric hospital, and mostly for mobility rehabilitation. According to Dong Nai provincial department of health, CBR was implemented in 147 communes and wards with a total of 47 community-based rehabilitation sites. Dong Nai also had day-care centers under DOLISA, but limited numbers of CWD could access this service. This proved to be effective in engaging children even the most difficult ones with mental disabilities (case study 10-year boy with mental retardation) [6].

Staff support and counseling to CWD/family

Research suggested that the qualification of rehabilitation and counseling was still limited, even within project-supported areas. This is because the personnel working with CWD and families were generally short of professional training and of continuous technical support, especially at the grassroots level. Health care for CWD generally did not emphasize detecting and preventing risk factors for disabilities whereas rehabilitation training for village health workers partially met the demands of children with mobility problems, but not for the others. Given the inadequate staff training, common staff shifting or changing further challenged the situation.[15]

Collaborations among stakeholders

Overall, there was inadequate collaboration and coordination among different sectors working with CWD. Education, health, and social protection services, the three key sectors generally worked in separate systems. This inadequate collaboration could result in errors in the identification of CWD, and untimely interventions for needy CWD [5, 6, 15].

Research also suggested that local stakeholders were crucial in supporting CWD but they were not fully mobilized[15]. This is because the inter-disciplinary partnership was an existing function of each community, and potentially promised success for community-based activities. Still, without the support and direction of the national government in supporting CWD, there seemed to be little motivation to take action.[1] Even in project-supported locations, the task assignment, roles, and coordination of commune and village stakeholders and local sectors might not be clear in every step of the project, thus making the collaboration challenging. Potential partners at the commune level such as Youth Union and CPFC (Committee for Population Family and Children) who have the capacity to advocate for children’s rights were not mobilized to participate in the implementation of related activities. [15]

Communication and feedback between NGOs, local implementers, and different stakeholders, although crucial in benefiting CWD, can be inefficient. Some research revealed that late and cumbersome communication among such stakeholders could generate misunderstandings and lost opportunities for CWD and related stakeholders. [15]

Social and community contexts

Social attitude towards CWD and their families has seemingly become more sympathetic and understanding [3, 11]. In Da Nang for example, community members generally felt it was their nature to give ‘their helping hands to the less unfortunates in the community’.[11] A community-based survey found that the vast majority of CWD living in households reported that local people had positive or favorable attitudes towards them (i.e. treated normally or with kindness/sympathy).[3] Moreover, the public, especially younger people held a strong respect and confidence that CWD would pursue a good life if they were given adequate conditions (family care, education, social services) [11].

However, both social and self-discrimination existed in different corners of the country [1]. In some parts of the country, cultural norms prevented CWD from enjoying social events. In Da Nang, for instance, taking CWD out in public holidays was seen as a taboo – and sometimes considered as bad luck or even of ill fortune.[11] At times, stigma and discrimination against CWD prevailed which largely contributed to the isolation of CWD and their families in their social integration. [5]

Feelings of shame and fear of rejection by the public even stopped many families with PWD from seeking opportunities for advancement and integration into mainstream society [1]. For CWD, self-discrimination (perception of being unattended and left behind) was even more critical and devastating as they were deprived the opportunities of inclusive education, entertainment and community activities[11].

Self-discrimination and isolation were more problematic with children having intellectual and behavioral disabilities[11]. They often had fewer friends and had lower participation in school, work, and daily life activities. This group also tended to report that they will not being treated well by local people in the community or by staff in the institutions.[3] Self-discrimination was less obvious among CWD who attended schools or vocational training and other social activities. This is because they had more friends and networks in which they could participate actively. [3]

Social attitude towards CWD differed remarkably for different types of disabilities. It was more normal to accept and integrate children with hearing/visual/mobility impairment than to do so with children with intellectual or behavioral problems. This is because the former CWD were more likely to have school friends and to interact with other community members. They were more likely to receive the sympathy and friendship of their neighbors, and thus enjoyed better social and intellectual development.[11]

Children without disabilities held caring and supportive attitudes towards CWD. Still, they commonly treated CWD as ‘pitiful and needy”. That notion indirectly defined their helpful behavior as charity and feeling of pity rather than actual inclusion of CWD into their world. At schools, feeling conscious of helping out CWD; copying down lessons; talking to them; helping them up and down stairs; and escorting them home were some typical examples of caring attitudes and behavior of non-disabled children towards CWD.[11] Non-disabled children living in communities also expressed their sympathetic and cooperative attitudes towards CWD as ‘kind, cute and tolerant of others’. Nevertheless, discrimination such as teasing and bullying existed in a small portion of non-disabled children. [11]

Authorities’ awareness and attitude

Support from local authorities and staff largely depended on their individual interest and enthusiasm, without any systematic guidance or instructions from higher levels. In those villages whose heads were enthusiastic and proactive, families of CWD received more support through their regular visits.[11]

Policy and laws supporting CWD

Much effort and progress has been made in developing policy to ensure the integration of people with disabilities into all aspects of Vietnamese society. Besides major policies issued during the last few decades (i.e. constitutions in 1959, 1980 and 1992 all had regulations protecting PWD) [1, 2, 14], Viet Nam has just put forward a new law on disabilities which officially came into effect on July 13th 2010. This law is a step above and beyond the earlier legal documents to ensure adequate implementation of the rights for PWD and CWD including convenient and full accessibility and availability to essential public services and ensuring better opportunities to realize their rights [16].

Given the prevailing discrimination and stigma against the disabled people in education, at work places, and in the community, the effort to protect the rights of CWD still faces many challenges, especially for the poor[17]. Identification and reporting of the abuse of children with disability was difficult due to the absence of a comprehensive child protection system[8]. No investigation and assessment component for responding to reports of child abuse existed either. Only the Law on Handling of Administrative Violations and the Criminal Procedure Code was available for handling complaints.[8]

3.4. Some insights on helping strategies

Overall notes

Much effort has been made to ensure the comprehensive integration of CWD into society through improving quality and increasing accessibility to education, health care, rehabilitation, employment, and policy areas. Nevertheless, while laws and policies tend to create more and equal opportunities for all types of disabilities, disabilities programs in Viet Nam seem to be confined to mobility, vision and hearing impairments.[1]

The last two decades have witnessed remarkable progress and achievements in health, education, and out-reach activities for CWD. Staff training and the production of guidance manuals and materials formed the most critical parts of such progress. However, inadequate training and facilities, shortage of implementing budgets, staff changes and lack of collaboration among different sectors, were big challenges for service expansion. See more details in the institutional contexts discussed earlier.

Public awareness raising

Public awareness raising activities were implemented through both mass media and community-based settings. Mass media, public events and campaigns were implemented nationwide but lacked the power to reinforce a shift in overall attitudes of society towards the full integration of people with disabilities. Particular examples of this communication channel were the National and International Disabilities Day events, as well as media articles on disabilities issues.[1]

Communication at grassroots level which involved concrete actions from local staff (health and education) largely supplemented the overall effect of the mass media campaigns above. For example, interventions supporting home-based identification and care with periodical staff visits proved to be effective in raising public awareness of CWD. [15] But this model was limited in scale.

Print materials such as leaflets, booklets, and flyers became important resources for PWD, their families and personnel working with them, but did not reach a larger audience. The materials covered a wide range of topics from prevention of disabilities, early identification, early treatment and intervention (pre-school)[18-21], and rehabilitation of different types of disabilities[22, 23], especially community-based and home-based rehabilitation manuals [24, 25]. Guidelines on inclusive education of different types also became a common tool for teachers at inclusive schools, and even for parents of CWD[26-30]. Commonly, such educational materials were accompanied by different disabilities assessment tools intended for teachers' use [31]. On the whole teachers worked independently at inclusive schools, but sometimes they worked with parents in accessing their children’s abilities and setting up school curriculum for them. [13] In such cases parents got some home-based training for their collaboration with teachers. Nevertheless, these materials and collaborative initiatives were limited within project areas, but not largely accessible to the public.

This model facilitated the cooperation between family and school, and effectively mobilized family resources to assist the learning of CWD.

There is a general feeling that communication through the above channels addressed little or nothing about the rights of CWD. In some areas, such rights were communicated but often in a separate arena from existing activities of the locality. Research suggested that communication on the CWD rights should be integrated into existing activities to reach large audience in a systematic way.[15]

Parent-teacher cooperative models

The home-based parent-teacher cooperative model promised to be effective, particularly with early interventions for children with severe disabilities. A recent study on home-based interventions for pre-school children with intellectual impairment through the parent-teacher cooperation proved effective in Viet Nam. This study examined the impact of a 1-year intervention program for children with intellectual disabilities. Parents in the study received some training to work with their children through modeling and coaching by teachers during weekly home visits. Results showed that children in the intervention group improved significantly in most domains of adaptive behaviors, and also performed significantly better than the control group in the areas of personal care and motor skills. [32]

Self-help groups

Self-help groups have emerged for over a decade as an innovative strategy for self-empowerment of PWD. Reported benefits from these groups included increased individual self-confidence and personal life satisfaction. But lack of leadership and legal status for operation prevented this strategy from furthering and sustaining its impact on the members.[1] In the long term this model should receive assistance for better maintenance and development to create collective power in caring for CWD.

Inclusive school with friend circles

Friend circles were initiated within the inclusive education implemented through CRS. They proved effective in mobilizing community resources and promoting social support among disabled and non-disabled children. The circles were basically peer groups made up of students who study well and live close to the disabled child. Such students volunteered to help CWD with assignments inside and outside the classroom. The Circle of Friends actually help children with disability succeed in school and break down barriers to their full participation in the community.[7]

IV. RESEARCH METHODS

4.1. Data collection tools

The team used desk research, consensus meeting with provincial leaders, in-depth interviews, focus-group, and home visits with case studies to explore the data.

Desk review

The desk review was conducted about 2 months before the fieldwork and involved a large number of existing IEC materials, available national publications, and reports on CWD in Viet Nam. This process resulted in a multi-faceted framework presenting key issues for CWD, major determinants for such issues at different levels (CWD, families, community, and institutional contexts), and some insights on intervention strategies to support CWD. That framework actually informed the data collection tool development and helped enrich the data during the fieldwork (Figure 1).

Consensus meeting with provincial leaders

On the first morning of the fieldtrip, the team met with key provincial leaders in charge of CWD to ascertain the overall situation of CWD in each province. The findings from such meetings led to the re-adjustment of the tools and suggested the team meet other rich informants.

Focus group discussions

A total of 24 Focus Group Discussions (FGDs) were conducted in the two provinces with parents of CWD; parents of children in inclusive schools; children in inclusive schools; CWD, and teachers of inclusive schools. The major data collected in FGDs were knowledge on CWD; accessibility and challenges to health/rehabilitation, education, information, employment services; values and life skills of CWD; social attitude and support; policy implementation; and multi-sectoral collaboration. Values, life skills, social attitude and support formed large part of most FGDs with children.

In-depth interview (IDIs):

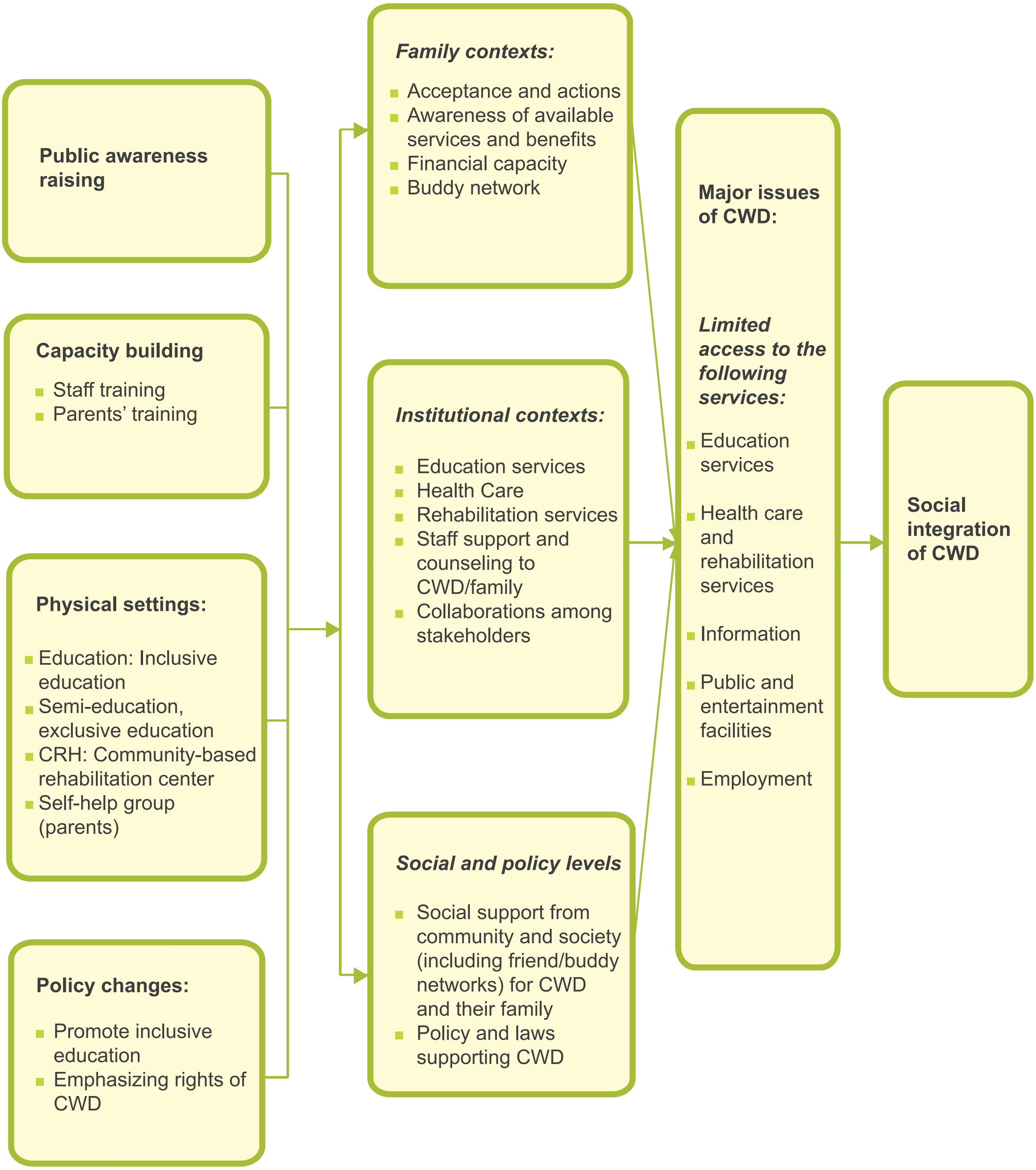
A total of 21 IDIs were conducted with members of provincial departments, NGOs, mass organizations (e.g. VWU, YU), teachers in inclusive and exclusive schools, and health care providers. Major themes collected in IDIs were similar to those with FGDs, but more subjected to probing and the in-depth exploration of the information patterns revealed during FGDs or from previous data-collecting attempts.

Home-visits and case studies

The team observed a total of 6 families with CWD for different purposes: to see their rehabilitation efforts and challenges (2 families in Dong Nai), and to build up 2 case studies on CWD issues (1 family in Dong Nai, 1 family in An Giang). The team also visited 2 other households with children of severe disabilities to see their family contexts and challenges.

Visit to a household with a children with disabilitity, Dong Nai (Rehabilitation)

Figure 1: CWD Analysis Framework



4.2. Sample size

Table 1: Sample size

Data collection tools	Sample size		
	Dong Nai	An Giang	Total
CONSENSUS MEETING			**3**
UNICEF staff			1
Provincial leaders (education, social protection, women)	1	1	2
FOCUS GROUP	**12**	**12**	**24**
Parents with CWD	3	3	
Parents of non-disabled children	2	2	
Inclusive school teachers	2	2	
Non-disabled children in inclusive schools	2	2	
CWD in inclusive schools	2	2	
CWD not going to schools	1	1	
IN-DEPTH INTERVIEW (IDIs)	**10**	**11**	**21**
Leader of children protection (province/commune)	1	2	
Exclusive school teacher	1	1	
Provincial/commune women union	2		
Commune vice-chairman	1	1	
Health care provider (District/commune/village rehabilitation staff)	3	4	
District and commune CWD staff	2	2	
Member of association of disabled people		1	
HOME VISITS	**3**	**3**	**6**
CASE STUDIES	**2**	**1**	**3**

4.3. Study sites

The study involved two districts, each in one province: Dinh Quan district in Dong Nai and Chau Phu district in An Giang. These districts were selected as the primary study site because of their higher concentration of CWD and related intervention strategies (according to local authorities). The two districts are also among the poorest districts of the provinces and thus more likely to provide better views of CWD regarding socio-economic contexts and challenges. Interventions based on these two districts would, therefore, better address the CWD situation in the two provinces.

4.4. Data collection

Desk review

The research team searched publications and available documents (both electronic and hard copies) for secondary review through UNICEF and its partners. The principal investigator (team leader) undertook the entire desk review and proposed a holistic research framework for the primary data collection process. See that research framework under Annex A.

Qualitative data collection

Five researchers, experienced in social and economic sciences research, took part in the fieldwork. The researchers worked in pairs to facilitate FGDs (one facilitated while the other took notes), but they individually conducted the interviews. They used tape recorders in both FGDs and IDIs to ensure the integrity of the information collected. Each FGD took one hour and a half whereas IDIs took about 45 minutes. Note that for FGDs with children, especially CWD, the researchers asked them to draw "paintings" before probing for in-depth information underlying the products. The major themes for painting including: likes and dislikes about life and school; experience and imagination of a CWD; and dreams for life.

A focus group with CWD (10-15 years going to school, Dong Nai)

4.5. Quality control

Different techniques were used to ensure the quality of the data. First, the rigorous research process allowed room for verifying reliability and validity of the measures. Second, all data collectors were trained by the principal investigator to standardize data collection tools and fieldwork procedures. Third, fieldwork was reinforced and supervised through interaction between the research team and the two UNICEF supervisors to resolve difficulties arising during the fieldwork. At the end of each fieldwork day, the team met to discuss the lessons learnt and adjust fieldwork plans. On the last day in each province, the team also shared key findings with provincial professionals and officers, and thus had a chance to clarify the findings and to get more input from the participants

4.6. Data analysis

The principal investigator, together with his colleagues, started to analyze the field data based on the proposed framework and themes. He then analyzed all fieldwork notes (from IDI, FGDs, home visits, and informal meetings with key informants) using Nvivo Version 2.0 which supports Vietnamese fonts. He generated major themes and key findings out of the process, and produced both descriptive statements and quotes accordingly. Vietnamese quotes and analytical texts were translated into English only after the analysis was completed to keep intact meanings of the data.

V. RESEARCH FINDINGS

This section will provide detailed findings around the key research questions. It begins with an overall discussion of the available database on CWD in the two provinces to provide a background for specification of all relevant findings that come later. The second part provides findings on the knowledge of the study participants (parents, kids, and adults) about CWD with the two major aspects: definition and classification of disabilities and early prevention, identification and intervention against disabilities of all kinds. The following sections elaborate the findings on various sectors and services: health care and rehabilitation; education; access to information; public and entertainment services; and vocational training and employment. Within each of these sectors/services, the author elaborates on the status-of-quo of the situation, involving both opportunities and barriers for CWD to ensure accessibility and quality of services for CWD. Commonly, the elaboration also incorporates discussion on knowledge, attitudes, and behaviors of both family and service providers and institutional contexts in relation to ensuring the accessibility of CWD to such services. The part on "access to information alone" specifies on communication capacity of the two provinces regarding available channels, quality of communication, and audience. The next part talks about perceived values and life skills of CWD. It, in fact, elaborates on CWD's perceived values of their social relationships and networks (with friends, teachers, community members) and of their own (through self-reflection of their dreams and aspirations). The last part, discusses attitudes and roles of family, society, and local authorities towards CWD. Findings from this part serves as a cross-cutting background for us to see how others perceive CWD and the need for a joint-effort in ensuring the rights for CWD.

5.1. Database on CWD

Social function-based classification of CWD

CWD in two provinces are classified into four key groups: the group that is nurtured at social protection centers; the group that is learning at specialized schools for CWD; the group at inclusive education; and the group that lives in the community. Followings are typical features of each group:

The group that is nurtured at social protection centers ranges from 0-18 years old who are either orphaned or abandoned children... This group consists of those children with intellectual impairment and deficiency (mental illness, epilepsy, autism); multiple disabilities (various types of disabilities in one child); and severe innate defects like hydro-cephalous, cerebral palsy. On the whole, these children can not take care of themselves. In Dong Nai, this group is distributed in 22 social protection centers for orphans and CWD (3 of which are state-run centers and the rest are private ones). Most of these centers are located in Bien Hoa and some in adjacent suburban districts. The number of CWD being nurtured in those centers comes to almost 3,500 (according to the report as at the end of 2009 by Dong Nai social protection center). There are also some charitable units that spontaneously receive CWD and orphans. These units are managed by kind-hearted individuals, but are not however, under the control of Labor and Social Welfare Service. There are no concrete figures for the number of children in these units. Meanwhile, there is only one social protection center in An Giang which currently nurtures 17 CWD and orphans. There is no evidence of the existence and operation of charity units like those in Dong Nai. Most of these social protection centers primarily work on nurturing the children, but are not adequately equipped to teach the children yet. Bien Hoa nurturing center for orphans and CWD (state-run center) is one exception – the children there are also taught to learn (Vietnamese, math), living skills (communications, learning of self-values), and some handicrafts (knitting, music, and hair cutting). Some of the children have been able to learn vocations and applied for jobs at some enterprises in the same locality.

The group that is learning at exclusive schools (specialized for CWD) consists of children from 6-14 years old (some are even older as they enrolled later). They have ability to learn and make progress (according to the teachers' enrollment assessment). The children in this group are mainly those who suffer from hearing and visual impairment. The exclusive school in Dong Nai also accommodates children who are retarded but able to learn. There is only one exclusive school in each province with

Focus Group discussion with children with disability in Dong Nai province a maximum enrollment capacity of 200 children (in Dong Nai) and 700 (in An Giang). Each school recruits 20-35 pupils per school year (in both provinces). They are taught the elementary schools' syllabus (over a period of 9 or 7 years instead of the 5 years put forward by Ministry of Education). Contents are adjusted to pupils' specific needs. In addition the children are given vocational guidance and taught some simple occupations that are relevant like knitting, household arts, hairdressing, massage, and aptitude subjects like music. Some visually disabled children have been able to learn how to play musical instruments and played in a music band (An Giang exclusive school).

The inclusive education group consists of children who learn together with non-disabled children at local schools. Most of the children in this group suffer from mobility disabilities or minor disabilities or some functioning deficiency like visual, hearing impairment, harelip. A small number of them suffer from intellectual impairment; however, they are able to follow teachers' instructions. In theory (based on talks with staff in charge of inclusive education and social protection in the two provinces), children at social protection centers or exclusive schools can join inclusive education after a period of learning there and under favorable circumstances. However, in reality, such scenarios have not yet occurred. Children in this group are given the chance to learn with non-disabled children, nevertheless, there are separate lesson plans for them depending on their learning ability. The research team has not got precise data on this group yet.

The community group consists of children that have never gone to school or those who have left school. The group that has never gone to school include pre-school aged children and those suffering from severe disabilities (mostly from cerebral palsy, intellectual impairment, and behavioral disorders) so they can not look after themselves and almost all lack the ability to communicate effectively. The group that dropped out of school consists of the children who suffer from severe mobility disabilities (they can not walk) and their families do not have time to take them to schools; those who suffer from minor impairments but their families are so poor that their parents have to earn their livings daily and can not afford to send them to school. While there is no concrete data on the number of CWD in the community group, officers in charge of CWD of the two provinces estimated that this group made up the majority of CWD. The community group is directly taken care of by their parents or relatives while not receiving any significant education or learning. Some rare CWD in the community group received some education from their educated parents or relatives. These CWD were mostly able to learn but were rejected for enrollment (see for details in Case Study III).

Reporting and supervision system on CWD

The detection, reporting and supervision system on CWD is not consistent among the three sectors: social protection, education, and health care, which leads to different reports on the numbers of CWD in each sector. For instance in An Giang there remains a big disparity in the province's total numbers of CWD between Education Service and Labor and Social Welfare Service. By the time of the research, the social protection center received 17 orphans and CWD left by their parents; 694 children were learning from kindergarten to elementary level at the exclusive school for CWD. According to the estimates by the provincial children protection department, the proportion of protected children in those above two centers is rather high compared to the total number of CWD in the entire province (1,900 by the end of the year 2009). According to the report by Education Service (until December 2009), however, there were was a total of 3,017 CWD out of 5,149 CWD under 18 years old who were learning at elementary inclusive classes.

Basic reasons for the disparity lie in inconsistency of criteria and definition of disabilities between the two Services and of the surveying, detecting, reporting and supervision techniques employed in the above-mentioned three systems. Education Service tends to include CWD up to 18 years old (school learning ages) and includes cases despite of disabilities level. Meanwhile, Labor and Social Welfare Service include children up to 16 years old and only consider severe cases because it cares about the assurance of incentives and rights for severe CWD. Health Care Service does not produce its own statistics and is dependant on either of the above-mentioned Services for its data on CWD. In addition, each sector possesses its own system of surveys, reports, and supervision, however, the three sectors commonly share collaborators at grassroots level - they are the ones who directly carry out the surveys. Once a sector needs to get data, the sector sends an official dispatch to a district that gives instructions to the commune, which, in turns, assigns collaborators to do surveys and report back to the commune. At times, the commune's people (sometimes together with the district's) in charge of children cross-check some cases to verify the quality of the survey data. Still, the entire process takes place using a strictly top-down approach without any agreement on the information collecting method and information quality. This sometimes causes unfairness and wastes resources. For example, according to a person in charge of elementary inclusive education in An Giang province "One commune sent a list of 30 severe CWD, however, when we went to re-check, none of them turned out to suffer from severe disabilities at all." There should have been one health care expert besides the collaborators who directly collected data in order to assure the information quality. More regrettably, survey officers were instructed with documents without any detailed training on survey method and quality assurance.

Luckily, at the moment, An Giang pilots a synchronous survey on CWD by using an integrated survey questionnaire developed by Ministry of Health within a framework of a collaborative program with UNICEF - Child-Friendly-Provinces (Tinh Ban Huu). The questionnaire will be jointly utilized by the three sectors: education, health care and social protection. Accordingly, statistics on the numbers of CWD in the province will be converged within a general co-coordinating body - the provincial social protection Department. Those officers who directly collected data were trained simultaneously to standardize methods and quality. There should still be a force of interdisciplinary, multi-level supervisors from provincial level down to communal level to assure quality for the surveys. At the time of the research, An Giang has piloted surveys applying this method in 7 suburban districts. No report has been made on this survey process though.

5.2. Knowledge on disabilities in children

Definition and classification of disabilities

Disabilities from children's perspective

For groups of children from 10 to 18 years old, regardless of their schooling status, definition of disabilities is often synonymous with "handicapped", but mostly reflective of a shortage of, or deformity in one, or many body parts/functions. This pattern was quite homogeneous in both provinces, and largely formed within their observation, experience, or imagination of disabilities. For example, when asked to give out practical examples on CWD (telling or drawing), CWD groups often gave examples similar to their current disabilities whereas the non-disabled kid groups commonly drew the image of a disabled "child" which often lacked or had deformed one of body parts (like arms, legs, or a big head, being blind, wry neck, etc). Some of them tried to draw children with intellectual impairment but ended up writing down explanations and notes as they failed to draw the disabilities. Most of the study children gave out one example or a story at the most (even with repeated probing during focus group discussions). Note: there were more CWD in Dong Nai, so the children found it easier to reflect an image of a CWD than those children in An Giang - where they had to present that image from their own imagination.

Classification of disabilities was also simple and consistent among children's groups and partly showed children's physical activeness. Most of the children's groups tended to classify disabilities into two key types: normal disabilities (which means normal ability to walk and function) and abnormal disabilities (which means an inability to walk, to learn - to understand and communicate). For most of them, normal disabilities was the very minor disabilities whereas abnormal disabilities was the very severe disabilities. The following quotation reflects the general perception of severe and minor disabilities in the children's eyes:

> *Severe disabilities mean paralysis (lying still), being one-armed, armless and one-legged, inability to act, learn, and do anything at all whereas light disabilities mean dumbness and deafness, and mouth deformity, etc., Children suffering from light disabilities can act and enjoy themselves.*
> (The group of school non-disabled children in Dinh Quan, Dong Nai)

Disabilities from adults' perspective

The adults in this research are more aware and had a more comprehensive perception of the classification of disabilities. For them, disabilities are not simply physical malfunctioning but also included spiritual wounds and economic pressures on their families. The most of mature interviewees (or those in the focus group discussions) quickly shared their knowledge on disabilities as both physical and mental deficiencies. Many of them could easily give illustrative examples of a disabled child. Like children's groups, the examples mentioned by the adults were the most related to mobility disabilities (cerebral palsy, being one-armed, armless, lame) and intellectual impairment (Down Syndrome). As usual, examples of hearing and visually impaired children and other types of disabilities were the last to be mentioned by adults (often after the interviewers probed “is there any other example?”). Examples and stories about CWD in Dong Nai were always diversified with more details than those in An Giang, probably because CWD and types of disabilities in Dong Nai are more common than in An Giang.

According to the adult groups, disabilities, in whatever type, all mean psychological, emotional, and material injuries, not only for CWD but also for their families. Many people in this research, regardless of their social classes, working positions and with or without CWD, agreed that “those disabled children are all disadvantaged children”. They often associated the psychological and material injuries of disabilities with those children who suffered from severe disabilities and could not take care of themselves:

> *CWD are more disadvantageous than non-disabled children so they should be loved by people. Those who suffer from severe disabilities need caring by a family member who stays at home every day, thus their families get poorer and poorer*
> (Parents of non-disabled kids, in Phu Vinh commune, Dong Nai)

The adult groups had a much more complicated way of classification than the kid groups as they not only based their classification on the severity of disabilities, but also on causes, contexts in which disabilities arose, and body parts' functions. Like the children's groups, they first classified disabilities into two levels: severe and minor. They thought those kids who suffered from severe disabilities could not walk or look after themselves. Some of them called it as the state of “botanical living” or “disabled” (the parent group with non-disabled children in Phu Vinh commune, Dinh Quan, Dong Nai). Many of them, especially the parent groups (of both non-disabled and disabled children) considered it as a kind of “entire handicap” and it was a fate which could not be changed. Some of them grouped those kids with uncontrollable, behavioral disorders or intellectual impairments “they cannot understand - do not know, do not remember anything at all” into the type with severe disabilities. They also thought that those children with minor disabilities could still walk, look after themselves and learn.

Besides, the adults also classified disabilities based on causes and contexts in which disabilities arose. Interviews and focus group discussions showed that there were three main groups of disabilities in line with three groups of causes that were recurrent in both provinces. The first group was innate defects (meaning disabilities that arose from fetus and kids being born with congenital defects). They often mentioned such examples as: Down syndrome, hair-lip, cleft palate, being one-armed or armless, lame, and those stemming from the effects of dioxin, etc. The second group was associated with acute health conditions which had not been treated in time (“high fever”, hence paralysis - called by them as “paralysis”, however, actually it was cerebral palsy. A few of them included malnutrition and incomplete vaccination into this group. The third group was due to accidents, parents' carelessness leaving their kids alone, so they fell down, got burnt by boiling water, fell out of trees, and had traffic accidents, etc. Finally they also classified disabilities based on body part functions like hearing impairment "deaf", visual impairment "blind", cerebral palsy, intellectual impairment (dullness, Down's Syndrome), harelip, "innate" cleft palate, and mobility disabilities "one leg crippled, one hand disabled". Notes: those words in quotation marks "…" are the very words used by the respondents.

Noticeably: among adult groups, the groups of teachers, officers in charge, health care officers were more likely than the parents' groups to classify disabilities based on contexts in which disabilities arose, and causes besides functional classification. This form was homogeneous in both two provinces.

Causes of disabilities

Awareness of causes of disabilities is not sufficient or precise and there is a clear differentiation between the kid and adult groups. The kids did not often care about nor explain the causes of disabilities in any detail. When asked about causes of disabilities, most of the kids shook their heads, saying they did not know. Few gave confident answers. However they answered, the causes listed by the kids fell into two types: innate defects and disabilities following acute diseases or accidents after birth.

Explanations on causes of disabilities by the adults were much more complicated but distinct for the two provinces. There were nine causes mentioned by the adult groups as follows:

1. Fetus malnutrition
2. Insufficient vaccination
3. Pernicious diseases that were not treated in time
4. Being deserted by parents during first years of life
5. Accidents
6. Being affected by dioxin.
7. Due to the chemicals used in weed killers and pesticide
8. Heredity (gene change/mutation)
9. Due to the fact that parents do not live virtuously ("immorally") so their children are punished with disabilities by god (especially with the disabilities group of cerebral palsy and intellectual impairment)

The popularity level of those causes, however, is clearly different between the two provinces and among the adult groups. For instance, in An Giang, causes of fetus malnutrition; disabilities after a pernicious disease that is not treated in time; insufficient vaccination; accidents; and being punished with disabilities by god were common. Meanwhile, in Dong Nai, causes of dioxin, chemicals to clear weeds and pesticides were almost always mentioned at all discussions and in-depth interviews by all subjects. Perhaps the popularity of these two causes overshadowed the respondents' awareness of other groups of causes. This was really dangerous for the community's health due to the omission of the causes to prevent disabilities.

Noticeably, while the groups of teachers and officers at all levels in An Giang put forward many causes of disabilities, the parent group with kids of severe disabilities in An Giang were very vague about those causes. They often kept silent when being asked about causes to disabilities or at the most replied that 'they do not know why it is so". Following quotations illustrate this statement:

> *I do not know why he/she was born so. Or perhaps this was his/her fate*
> (The maternal grandmother of a 7-year old kid who suffers from cerebral palsy, in Binh Thuy, Chau Phu, An Giang)
>
> *I do not know why he/she suffer from it. I have heard other people saying again and again that my family misbehaved so my kid suffers from it*
> (The father of a kid who suffers from down disease, in Binh Thuy commune, Chau Phu)

Following table summarizes causes of disabilities for the two provinces with notes and explanations of the research team.

Table 2: Locally-defined causality of disabilities

Causes of disabilities	Respondents' explanations	Commonality Dong Nai	 An Giang	The research team's observations
1. Fetus malnutrition	Mothers do not get enough nutrition during their pregnancy, which leads to malnutrition and insufficient development of the fetus.	Rarely occurring	Common	Many teachers, health care workers and officials in charge of communual sectors in An Giang emphasized on this cause. Meanwhile in Dong Nai, this cause was rarely mentioned.
2. Due to insufficient vaccination	Due to insufficient vaccination, children often catch serious diseases that cause disabilities.	Not occurring	Very common	Officials in charge, especially health care workers in Chau Phu district, An Giang commonly mentioned this cause: *"About 10 years ago, the children were rarely given with full vaccination because they were not taken care of by their parents, therefore, they often caught diseases and got disabled"* (The commune's health care workers…, Phu Chau)
3. Getting disabled after a pernicious disease that is not timely cured	Children who were born non-disabled, but got 'paralyzed" and "mentally impaired" after suffering from a disease that was not timely detected and treated.	Rarely occurring	Very common	Almost all groups and individuals in An Giang presented this cause. Many of them told that they witnessed the children were born non-disabled but after a high fever and treatment, they got "paralyzed" (cerebral palsy) and "mentally impaired". This cause was seldom mentioned in Dong Nai, either.
4. Being deserted by parents during first years of life	Because parents did not have time to take care of their kids, leaving them at home alone or with somebody who did not even have ability for communication	Rarely mentioned	Mentioned sometimes	The research team got a chance to witness a 9 year-old kid in Dong Nai who had not been attentively cared for during the first three years but left at home with a dog.

Causes of disabilities	Respondents' explanations	Commonality		The research team's observations
		Dong Nai	An Giang	
	(for instance, blind people who cared for CWD). The kids did not have chances to learn how to communicate and contact with other people so their ability for awareness and communication got reduced when getting older. They often suffered from intellectual deficiency. There were kids who did not have chances to contact other kids in the hamlet so they got afraid of strangers and restrained themselves from everybody. In some cases, they got to suffer from autism.			She has got habits similar to those of a dog so far. She has failed to do activities in a way a non-disabled kid of her same age does. The research team has not witnessed any such a case in An Giang. However, some teachers in Khanh Hoa commune and parents with 5-6 year-old disabled kids in Binh Thuy commune, An Giang told that they had ever witnessed such case of intellectual impairment.
5. Due to accidents	Accidents include: collision with vehicles, enjoying their times when climbing trees and fell down, suffering from burns of boiled water and fat…	Rarely mentioned	Common	Due to the typical feature in An Giang with gardening, children often climbed trees; fell down to get broken leg or arm, or brain trauma. Afterward, the treatment was not careful, leaving the children with disability. Besides, children in An Giang often suffered from burns of boiled water and cooking oil due to their parents' carelessness. Most of the parent groups with disabled children in An Giang mentioned this cause whereas this cause was rarely mentioned in Dong Nai.
6. Being affected by dioxin.	Parents take foods and drinks that contained dioxin left over after the war, which caused gene mutation to their kids.	Very common	Not common	Most of the respondents in Dong Nai reckoned that disabilities in the province were caused by dioxin. Many of them thought Dong Nai is the place that was scattered with much of dioxin – at present,

Causes of disabilities	**Respondents' explanations**	**Commonality**		**The research team's observations**
		Dong Nai	**An Giang**	
				there were many casks of chemicals that have not been dealt with yet. Few people in An Giang mentioned this cause.
7. Due to the use of chemicals to clear weeds and pesticide	Parents ate foods that were sprayed with chemicals to clear weeds and pesticide, causing genetic mutation to their kids (similar explanation with that of dioxin)	Very common	Not occurring	Most of the respondents in Dong Nai mentioned this cause. They emphasized that at present, the residents used weed killer in an uncontrolled way, any time and any where: *"At times, the weed killer was sprayed the previous afternoon, the vegetables were sold next morning. The vegetables looked very green and nice, however, obviously, the vegetables had just been sprayed with weed killer the previous afternoon"* (According to a father whose kids were non-disabled in Gia Canh, Dinh Quan).
8. Due to heredity (gene mutation)	Kids inherit the same defects that their parents had.	Rarely occurring	Rarely occurring	This cause was mentioned during some focus group discussions with parents with non-disabled kids in both provinces; however, it did not become a pattern yet.
9. Due to the fact that parents do not live with virtues (being immoral) so their children are maltreated with disabilities by the god	It means that parents do not live with virtues so their children are maltreated with disabilities by the god	Not occurring	Common	This cause was mentioned many times during several focus group discussions with parents with disabled kids in all researched communes in An Giang. Meanwhile, this cause was not mentioned in Dong Nai.

Early prevention, identification and intervention against disabilities of all kinds

Knowledge on prevention of disabilities

Knowledge on prevention of disabilities in children remained limited among the parent groups both with and without CWD. Most of the interviewees in this research did not take initiatives to prevent against disabilities nor officially learnt any preventive skills or measures. Whatever they knew and did was influenced by the national health care programs or mass media. For example, about 10 years ago, many kids did not get vaccinated - as many people in An Giang saw it as the cause of disabilities, but now most children have been fully vaccinated. Meanwhile, in Dong Nai where dioxin had remained an obsession, instead of taking risks as before (drinking stream water when thirsty), residents now take boiled water when going into the woods or tilling the fields (FG with parents with non-disabled kids in Gia Canh, Dinh Quan, Dong Nai). With the continuing careless and extensive use of weed killers in Dong Nai, however, there is no way of avoiding it even though residents knew about its latent, harmful effects (causing disabilities): “The residents in general, even me, would avoid the weed killer if only knowing for sure that it had just been sprayed the day before, otherwise, there was no way to avoid it.” (One father of a non-disabled kid in Gia Canh, Dong Nai).

Note that in An Giang, the adult group often mentioned accidents, fetus malnutrition, and diseases which were not treated in time, as common causes of disabilities, nevertheless, the residents remained indifferent about these cases. They did not take initiatives or were aware of preventive measures against these factors. A possible underlying reason is that the people here were very poor (they earned 30-50,000 dongs a day, including expenditures for foods) and they were mainly working for other people, so they did not have time to pay attention to, and take care of, their kids.

Knowledge on early identification and treatment of disabilities

Early identification depended on various types of disabilities. Physical impairments (legs, arms, eyes, lips and mouth, etc) were often detected right after birth or within 2-6 months (according to most of the parents with CWD in the two study districts). With intellectual impairment (Down syndrome), behavioral problems, especially cerebral palsy, the identification of the disease was often concealed by another serious disease. Late diagnosis would require much more effort in the nurturing and rehabilitation of the children:

> *... it was the same with my third kid. It was not until he got 2 years old, did I realize he suffered from it [deformed spine]. Accidentally I asked him to turn back, he could not turn his head only but the entire body. At the time, I found that his neck was bigger than that of non-disabled kids. I did not give him any treatment at all. Only when he got a fever, I brought him to the doctor and was told by the doctor that he suffered from deformed spine. He had been taking medicines for six months; however, the problem did not disappear. He only took tonic, not the medicines to cure the spine deformity.*
>
> (The mother of 2 disabled kids in Gia Canh, Chau Phu, An Giang).

Early intervention against disabilities was a problem in the two study districts (Dinh Quan in Dong Nai and Chau Phu in An Giang): the disabilities was either treated as it was getting severe or it was intervened early, but primarily based on folk experience. The reason lay with the long history of poverty among the local people. The residents of the two study districts mainly earned their livings by going into other people’s services (slash-and-burn cultivation, producing bricks and working as masons) with an average income of 30-50,000 dongs per day, however, the income was on and off. Only few employment opportunities existed for the larger number of people who were constantly searching for jobs. They had to compete against one another for employment and did not have time to take care of their kids. They often had to leave smaller kids to be cared for by elder ones or by other relatives who had lost their ability to work (some even sent their kids to be cared for by blind people - like the case in Binh Thuy commune). Only when their kids suffered from serious diseases, they would take their kids for treatment. Many parents, even after detecting their kids' disabilities during that treatment spell, continued not to treat their kids' disabilities, but either left it to fate or did not know what to do next to help their kids recover.

> *There is one 14 year-old boy in Binh My commune, Chau Phu district, An Giang, for instance. He was born with a soft piece of skull bone of about 5-6 cm in diameter. When he got 7 months old, his relatives detected that soft piece of skull bone so they took him for a medical check-up. The doctor also found that his right arm was paralyzed (he could not move it up or put it down) but did not give out any instructions for the hand rehabilitation. Neither did his family. Now he is 14 years old without being given any chance for rehabilitation.*
>
> (According to his paternal grandmother and the research team's observations at the focus group discussion with CWD who did not go to school).

That was the case of a disabled kid who although he was found to be disabled and taken to the doctor, he did not get any treatment afterwards. The two following cases involved very early intervention but without experts' guidance:

> *When my kid was 4 months old, my neighbors asked me why his legs were so stout and short, which was different from those of other kids. I did not take him to a hospital, but bought hot balm to massage his legs. I did so for long but the problem did not get better.*
>
> (One mother in Gia Canh commune, Chau Phu).

My kid got an accident and his legs got paralyzed. I massage his legs, however, I did it based on my experience only, not on any doctor's instructions (One mother of a kid with paralyzed legs in Gia Canh, Chau Phu)

The early identification of disabilities in children has yielded great hope for the children, especially those with mobility disabilities, even with cerebral palsy. However in reality, often these hopes are not realized. It should be noted that: those families which take their kids for early treatment often had relatives who were working in the health care sector and were better off economically. The following comments made by doctor Ha, the rehabilitation expert at Long Xuyen hospital proved this:

> *If cerebral palsy were early detected, for instance, within some first months, the treatment shall get very good. I have already rehabilitated kids of so early detection. It shall be very good if doctors rehabilitate for the kids and give instructions for their families to collaborate for treatment. The rehabilitation shall be easily gained. If kids' cerebral palsy is detected during the stage of soft paralysis, the possibility of rehabilitation shall be high. Once muscles get hard and rigid, it shall get much more difficult to gain rehabilitation.*
>
> *…What a pity! Few parents detect their kids' disabilities early and offer their kids with timely treatment. Those who detect their kids' disabilities often work in health care sector or have their relatives working in the health care sector. The treatment for those kids who came here early (usually within 1-2 months) was very good. Their relatives often work in health care sector. Their relatives detected the disabilities and advised the kids to be taken for medical examinations*
>
> (Doctor Ha, an expert on rehabilitation at Long Xuyen hospital, An Giang).

5.3. Health care and rehabilitation

Actual state of health care and rehabilitation

In general, CWD in the study sites did not get adequate health care and rehabilitation, but they received more attentive care for home-care and hygiene from their parents. Followings are some common patterns of health care for CWD in the two provinces:

Medical examinations and treatment for CWD

CWD's parents did not often take initiatives to take their kids for periodical medical examinations but only did so when their kids' disabilities got severe. Normally, a spell of severe diseases or a sudden and obvious changes in kids' activities (arm, leg shaking, or soft skull bone, stiff feet or suddenly softening arms) were primary reasons for them to take their kids for medical examinations. What a pity! When their kids' condition abated, they did not even continue offering treatment for their kids' disabilities..

> *Each time, my kids catch diseases, we will only take them to the district's hospital if they suffer from severe diseases, otherwise, with a slight fever, cough, flu, most of the times we just buy medicines from a nearby pharmacy to give to the kids.*
>
> (The parents of CWD of levels 1 and 2 in Gia Canh commune, Dong Nai).

Parents often took their kids for medical examinations and treatment at private health care units or bought medicines on their own for the kids, but were not interested in taking their kids to public health care units. The basic reason lay in the fact that health care workers, in addition to distributing medicines, did not thoroughly examine or treat the kids, neither did they offer detailed consultancy on the kids' condition to the parents. (See the section on health care consultancy and health care workers' attitudes for further details).

Kids in exclusive schools and in state-run social protection centers particularly got free-of-charge medical examinations and treatment through associated health care programs among those units and adjacent hospitals. The number of kids who enjoyed this care policy, however, was very limited

Rehabilitation

Parents often found ways to rehabilitate their kids either by themselves (based on their own experience), or by being instructed. However they showed impatience in maintaining practice regime and tended to withdraw when their kids' disabilities did not improve. In An Giang, almost all parents cared for and rehabilitated their kids themselves (CWD of the mobility group) based on their experience. They got practically no instruction from experts. For example, a mom of 6 year-old kid that suffered from cerebral palsy says: *"each time my kid moaned with pains in his legs, I will apply hot balm on his legs to massage. I was told with this method by my mom, however, I did not know whether it was effective or not. Besides that method, I did not know about any other method"*. Meanwhile, in Dong Nai, rehabilitation activity was deployed to the community.

Families with CWD of mobility (especially the group that suffered from cerebral palsy) were instructed with rehabilitation methods for the kids at home. Nevertheless, they often got impatient in maintaining the rehabilitation regime for the kids. There were many cases of failures whereas the number of successful cases was very small - this caused doubts in the parents and they lacked the motivation to continue their rehabilitation effort.

Visit at a household with a CWD, Dong Nai (rehabilitation)

Home-care and hygiene

While the majority of CWD (especially the severely disabled group of mobility, behavioral disorders and intellectual impairment) were not given full or sufficient health care, they were attentively cared in respect of home-care and hygiene. Parents and relatives' endless love for them taking the line that "they are disabled so they are more disadvantageous than other kids" was a motivation for those CWD to be given "tastier foods" and "more care". One kid with disabled left arm due to burn from boiling water, 17 years old in Binh Chanh commune, Chau Phu, An Giang narrated: "My parents and elder sisters love me much. They always reserve delicious stuffs for me. They are trivial things; however, they make me glad."

Another example is a mother in Gia Canh commune, Dinh Quan, Dong Nai who had a 16 year-old kid with such a severe intellectual impairment confided:

> *I do not go to work, but stay at home to care for her/him. Nobody else but me who can feed him. He can not eat rice but porridge, noodle food, and vermicelli. I will feed him anytime he wants to be fed… He went to a rehabilitation center (at the age of 6), those women who cared for CWD did not have time to feed him in the way I often did at home because they did have to look after many other kids. After some months, I found he was so skinny and pale that I loved him more and brought him back home…*

As for hygiene, although parents talked very little about the way to keep CWD clean, the research team did have practical evidence of careful hygiene for CWD via visits to those families with kids of severe disabilities. Specifically, the team visited three families with CWD in Dong Nai (two kids suffering from cerebral palsy in Long Binh ward, Bien Hoa and the remaining kid suffering from behavioral disorders in Gia Canh commune), and three families in An Giang (one kid with cerebral palsy in An Chay town, Chau Thanh; three kids with cerebral palsy in Khanh Hoa commune, Chau Phu, of whom there was two twin brothers). Most of them looked very clean without any sign of poor care. There were two exceptional cases of poor hygienic care: one kid with behavioral disorders and one 6 year-old kid with cerebral palsy always lay in the same place and suffered from interminable pneumonia. The one with behavioral disorders was always raking and turning up the milpa to create a litter to sleep in so her body was covered with soil and sand. Although the 6 year-old kid with very severe cerebral palsy looked clean, the air inside his house was foul smelling due to a lack of ventilation. The remaining households had airy and healthy atmospheres in which the CWD could play.

Among the disabled kids, two cases were particularly clean. Both of them were girls, 12 years old, suffering from cerebral palsy. One of them lived in Khanh Hoa commune, Chau Phu, although she could not walk or look after herself, she was given a well-ventilated room, the floor of which was always kept impeccably clean with barriers to protect her from falls. Anyone who entered the room had to leave their slippers at the door. The other girl could walk on crutches. She looked both clean and pretty, always smiling and with communicative looks.

Good typical cases

A small number, usually well-to-do households, cared thoroughly for their CWD and provided the best possible treatment and care for them. Kids in families of this type often made a lot of progress, not only physically, but also spiritually and intellectually. Such success was attributable to various favorable conditions such as: economic capacity; presence of people who gave regular and attentive cares to CWD and had knowledge and experience of the kids' diseases. Particularly important was regular contact with health care centers or experienced doctors. A typically successful case involved a 12 year-old girl who suffered from cerebral palsy when she was less than 1 year old. Her family was sensible enough to go to a health care unit which had used high-tech rehabilitation techniques (the provincial general hospital, Ho Chi Minh City's center of orthopedics) for over 10 years. Her family was able to afford all the costs of her treatment and rehabilitation. Moreover, her parents were both governmental employees with higher-than-average education level and belief in their kid's ability to recover. They taught their daughter. They also had relatives working in health care sector and often got advice from doctors on rehabilitation sector. Now 12 years old, the girl can walk around inside the house on crutches, read, write and do simple mathematical questions, communicate normally, draw pictures beautifully and has a sense of humour. Earlier she could not even walk by herself or tidy herself up. (See for details in Case Study number III)

Influential factors on patterns of health care and rehabilitation

CWD themselves and their families

CWD were prone to diseases, however, their parents lacked knowledge on disease prevention for them, so they were often unable to prevent diseases and unable to give treatment to the kids. Those CWD suffering from cerebral palsy were most vulnerable as many of them lay practically still in one place and were prone to pneumonia and ulcers. For instance, a 6 year-old boy in Long Binh, Bien Hoa, who suffered from cerebral palsy and had to be on his back, caught pneumonia constantly – one spell after another, despite his family and doctor's efforts. There was no other preventive measure for him other than his mother giving him daily antibiotics. This was a totally inappropriate treatment because although antibiotics could cure or prevent pneumonia, but they could also kill useful digestive bacteria unintentionally. This could have also contributed to his severe malnutrition (skinny, pale with his two thighs, arms and legs being raw-boned. His body parts were nothing but skin and bone).

Parents' knowledge and skills to rehabilitate their CWD remain limited: they either did nothing or they rehabilitated the kids based on their experience or gave up the rehabilitation effort if they found the child's condition did not improve. Almost all parents in An Giang with disabled kids in this research did not get advice for caring for their kids. All they could do was to rely on their own experience or traditional remedies (balm application, letting CWD to lift heavy objects…). For instance, a girl in Binh Thuy commune, An Giang, who was in 9th grade, was paralyzed in her left arm but did not receive any advice or care other than her elder brother tied a string into a brick and told her to lift it up and down repeatedly. In Dong Nai, although there was a rehabilitation program in the community, CWD's parents were not properly advised due to lack of attentive monitoring and support by rehabilitation collaborators. Therefore, they did not have clear orientation in assessing CWD's progress nor identifying the next steps of treatment or rehabilitation for the kids. Few parents knew how to rehabilitate the kids thanks to their close relations with officers on rehabilitation (for instance, the mom of the 12 year-old girl in An Chay, Chau Thanh, An Giang, the Case Study number III).

Moreover, the parents often lacked belief in their kids' progress so they got disheartened and failed to maintain the practice regime for their kids. This could be explained by the fact that the parents rarely experienced successful rehabilitation cases in the presence of omnipresent failures. They did not get full explanations from collaborators on the rehabilitation's benefits and effects so they became skeptical and gave up easily.

A major barrier for CWD to get medical examinations and treatment is the distance from their homes to the health care center. In addition was the impending loss of employment opportunities for their parents. For those households located near commune health centers the barrier did not exist: "CWD and their families can easily access health care services as there is a medical station in the commune and there are medical branches in hamlet… There are professional doctors working at medical stations and this is a commune which is near the suburban district's hospital." (The Vice Chairman of Gia Canh commune, Dong Nai). In reality, however, many households in the researched areas lived on milpa, sparsely populated areas far away from health centers. Villages might have a satellite health facilities, but this pattern was not common (for instance, Gia Canh commune). Even village satellites, failed to meet the residents' demands for public health check-ups which were often held at the commune health stations. In many cases, long distances, potential loss of employment opportunities, and lack of care from health care workers all contributed to the parents' decisions not to take their kids for public health check-ups:

> *Once there is a supportive program of medical examinations [public health check-ups], few people join in the program because most of them live very far away. Parents have to take a working day off to take their disabled kid out for medical examinations. They find it as very time-consuming while doctors and nurses performed their task without adequate care and attention. They only dispense milk or medicines but do not examine the kids carefully, which makes the parents not want to go as they will get no benefit*
>
> (Health care worker in Dinh Quan suburban district, Dong Nai)

Following is some comments by CWD's parents on barriers of distance and loss of working opportunities:

> *Each time, my kids catch diseases, we will only take them to the suburban district's hospital if they suffer from severe diseases, otherwise, with a slight fever, cough, flu, most of the times we just buy medicines from a nearby pharmacy to give to the kids. It is very far to go to the suburban district's hospital so I have to give up one working day and have to wait for very long.*
>
> (The parents of CWD of levels 1 and 2 in Gia Canh commune, Dong Nai).

Poverty and hard work were the main reasons for parents' unwillingness to take CWD for regular medical examinations and treatment or periodical medical examinations. This not only denied the CWD the chance to the complete treatment but at times also left the entire treatment process only

half finished. Poverty therefore sometimes deprived children of health check-ups, even those who had free medical check-ups and medicines available near their homes.. Many parents only took their children for examinations (1-2 times a year) as long as it did not mean they would lose out on a day's wages. They did not take their children for examinations if it meant losing their salary despite their awareness of a visiting health delegation within their area: "if taking my kids out for examinations, I will lose a working day" (One mother with a disabled kid in Chau Phu, An Giang).
Following is the quotation highlights the situation:

> *Most of CWD's families are poor, so it is too difficult for them to come to us for practices… There are many CWD in An Giang, however, I do not know how many of their parents are aware of practices as they are very poor. Traveling costs are not little for them.*
> (Doctor Hien, the dean of orthopedics ward of Long Xuyen general hospital, in An Giang)
>
> *I found my kid had the problem, not able to turn over, at his few months of age. I took him to a medical examination. As the result, I knew my kid suffered from cerebral palsy. The doctor gave my kid with medicines to take but the disease was incurable. My family was poor. We did not have money for the treatment so we had to give up*
> (One mom in Dinh Quan, Dong Nai who had a 7 year-old disabled kid)

The quotation below illustrates the regrettable incompleteness of a promising treatment process:

> *My kid got the treatment and rehabilitation right when he was some months old. When reaching 8 months old, I led him and he was still able to follow me. Afterward, I delivered second child and had to work whole day for my livelihood, otherwise, I did not have get enough foods to feed the two kids.*
> (The mother in Long Binh, Bien Hoa, Dong Nai
> with the 6 year-old kid who suffered from cerebral palsy and lay still in bed)

Poverty and children' disabilities often went hand-in-hand in creating a vicious circle, making CWD's families poorer and poorer and directly reducing motivations for health care, even extinguishing hope and effort for further the rehabilitation for CWD. These were the findings in both Dong Nai and An Giang, especially in the two study districts. Specifically, children with severe disabilities were often born to poor households (perhaps their disabilities were caused by insufficient health care) and in cases of such severely disabled children, each family commonly had to assign at least one person to stay at home to take care of the CWD. Thus, they would lose opportunities to earn money in addition to the cost of care and treatments for CWD.

Health care and rehabilitation system

Early diagnosis of disabilities

A key issue is a lack of community based CWD activities in An Giang and ineffective activities in Dong Nai. Advanced technology for early diagnosis of disabilities and for rehabilitation are now available at provincial hospitals, which could meet a small portion of CWD's demands. Both provinces have applied technical advances (3-D ultrasound and testing techniques) to early detect disabilities (in uterus). However, this service is available to only a minority of residents, mainly those in cities and those with high incomes.

> *With respect of techniques of early malformation detection and intervention right during fetus period, they are well applied in cities as mothers easily access high technologies… The ultrasound scan, malformation detection tests during gestation are not accessible to remote, distant areas due to lack of facilities.*
>
> (Doctor Thanh, from Expert Bureau of An Giang health care Service)

Meanwhile, the two provinces had not made any noticeable effort to boost the community's knowledge on the causes of disabilities, types of disabilities, early prevention and intervention against disabilities. According to personnel from various sectors including health care in this research, programs such as pregnancy tests, nutrition and vaccinations have been in operation for years at communes. However those programs did not mention disabilities.

Health care workers' counseling and attitudes

The health care sectors in both provinces did not have an effective health care counseling system for disabilities in children. This deficiency was highlighted by the health care workers' indifference to parents' confusion and ignorance of their children' health conditions and disabilities. This indirectly damaged the parents' belief in the public health care system, which in turn widened the gap between the parents and the public health care system. According to many parents of CWD in both provinces, they received practically no advice or counseling on diseases and caring measures for their CWD:

> *We all do not know about causes to our kids' disabilities. When taking our kids to doctors, doctors/ health care workers did not tell us why they suffered from such disabilities, they just gave our children medicines and gifts.*
>
> (The focus group discussion with the parent group
> in Binh Chanh commune, An Giang with CWD who did not go to schools)
>
> *Health care does not fulfill its roles. Most of doctors' and nurses' professional skills of medical examinations and treatment were not qualified. They purely examined and provided medicines, they did not offer any counseling or explanation or advice on disease relief measures.*
>
> (The focus group discussion with those parents in Khanh Hoa,
> An Giang with non-disabled children).

Unfortunately, even though health care providers had IEC documents readily available, they missed the opportunity to give instructions to parents. This indifference upset many parents:

> *When taking my kid to have an operation, I was given with a brochure on how to take care of kids by the doctor, however, there was general information in the brochure. It did not tell clearly about each disease, my family mainly got to learn about the diseases.*
>
> (The focus group discussion with those parents
> whose disabled children were going to school in Gia Canh, Dinh Quan, Dong Nai)

A consequence of this lack of confidence in the public health system was that the majority of parents took their children to private health care units or bought medicines themselves to treat their children instead of going to public health stations. This pattern was homogeneous in both researched provinces. Many people did not want to go to the health stations (i.e., commune health centers) even when they were entitled to health care insurance, simply because they thought "coming there, their kids will be given with cursory examinations, some medicines and come back home. They would receive any counseling or attentive care from the health-care providers at all". (The focus group discussion with those parents whose disabled children were going to school in Binh Thuy, An Giang). The importance of the health care workers attitude [mentioned above] is highlighted by the following: what parents expected more than medicines and money, was attentive counseling and a caring attitudes: *"We do not want to receive gifts, but only needed doctors to provide sufficient information and advise us on cares only."* (focus group discussion with those parents whose disabled children were going to school in Gia Canh, Dinh Quan, Dong Nai)

There were, however, health-care providers who were very attentive, whole-hearted and devoted to help CWD's families. That was the case of doctor Ha, a rehabilitation expert at Long Xuyen General hospital in An Giang. The research team visited the rehabilitation center and talked with her. Through her story, we felt she was enthusiastic, compassionate and thorough in her conversations. Also thanks to her, we knew a case of a girl who had been suffering from cerebral palsy for 12 years, and now she made a good recovery (Case Study number III). It was Doctor Ha who directly rehabilitated the girl, gave instructions to her family to assist her practice and when necessary, she referred the family to better resources. She wrote a recommendation letter to send the girl to Ho Chi Minh City's orthopedics center. So the girl's condition has improved remarkably thanks to doctor Ha's attentive care and advice. The health care sector in particular and other sectors in general really need caring officials like Dr. Ha.

Human resource

Health care collaborators have been operating for several years, but remained ineffective due to sparse land-areas, multiple tasks, lack of professional knowledge and skills, and modest incentives. Most collaborators who joined in this research had been working for many years in the health care sector (village health workers, population collaborators or volunteers). They undertook many tasks related to many different programs at the same time: such as health care, education, social protection, even rehabilitation for CWD (as in Dong Nai). This meant that they would do whatever was assigned to them by their seniors.

The key difficulty for collaborators lay in the fact that they undertook too many overlapping activities from different sectors over a large land area, which made traveling very hard. This was true for both study districts as households were located along milpa, so "it is very difficult to travel in remote and distant areas". As confided by a person in charge of rehabilitation in Gia Canh commune: "*The area under my responsibilities is very large with many households but only me who is in charge of it. At times, I cannot cover all tasks because I also have my own work".*

Many collaborators actually gave up work as the burden of carrying out multiple activities from different programs became too great. According to doctor Thanh, from the professional bureau of Dong Nai Provincial Health Care Service, there were up to over 20 different national health care programs. In addition salaries were very modest (at present, about VND 150,000/month - according to doctor Thanh again). This was another reason for many collaborators gave up work. The remaining mainly carried on because of a strong sense of community spirit and love for children: "*10 years ago, there were 4 rehabilitation collaborators in my commune. Three of them gave up, now that there is only me. I did the work voluntarily and mainly with my heart. The incentives were nothing, you know"* (One rehabilitation collaborator - Phu Vinh commune, Dong Nai).

Rehabilitation system

The current rehabilitation system, either at hospitals or in the community, only focused on mobility disabilities. To date is has not met CWD's practical demands. Dong Nai had both types of rehabilitation (rehabilitation at Pediatric hospital and in the community) whereas An Giang had only one rehabilitation center in Long Xuyen general hospital. The key problem in An Giang now is a lack of material facilities, equipment, and human resources for the rehabilitation system at the provincial hospital, and it still has to establish a rehabilitation network at district and grassroots level. In Dong Nai, while the rehabilitation work at hospitals only served a small group of CWD of mobility, the rehabilitation work in the community faced numerous challenges: lack of facilities; wastes of resources (i.e., trained rehabilitation collaborators did not perform their expected tasks; CWD's families were impatient and uncooperative with rehabilitation staff; lack of technical supervision and assistance for grassroots level; and lack of incentives for rehabilitation staff.

Health care policies

The policy of free medical examinations and treatment for children under 6 years old and for severe CWD over 6 year-old born to poor households was being implemented in the two provinces. However, it was not actually available to all beneficiaries. Every year in the researched areas, there were spells of free medical examinations for children under 6 including those with disabilities. For children over 6 years old, only severely disabled children (according to the list of social protection sector), who belonged to poor households, were entitled to health care insurance and free medical examinations and treatment.

Many poor households with severely disabled children, especially in An Giang, did not receive such help as they were not registered as poor or their poverty certificate had expired. Such families often did not have money to buy health insurance and obviously their CWD missed out on the chance for medical examinations and treatment of the state's free programs:

> *When my kid was little and going to Long Xuyen hospital for treatment, we got 20,000 dongs a day. At the time, I had a register of poor household and health care insurance. The register got invalid but it had not been re-considered yet. I shall have to pay 300,000 dongs of something if wishing to benefit from health care insurance. We did not have money to take out insurance so we had to give up*
>
> (One mom with a 7 year-old son in Binh Thuy, Chau Phu,
> An Giang, who suffered from cerebral palsy)

There remained severely disabled children of poor families whose parents were incapable of nurturing them and who never had the chance to receive free health check-ups. A typical example of this is a girl suffering from behavioral disorders (she had habits like a dog's) in Gia Canh commune, Dinh Quan district, Dong Nai province. Her mother left her when she was only three. She lived together with a young brother and her father whom the villagers referred to as "crazy" and "who can not even support himself". Still, she had never got any free medical examinations. Her aunt in-law recalled: "*there are spells of free-of-charge medical examinations, however, my niece has never been provided with a chance to get it. No one ever invited her for the check-ups*". This is an area where there is room for improvement by local policy makers. See for details in Case Study Number I.

A free program "orthopedic surgery– smile" existed for severely disabled children of disadvantaged families (mainly with harelip, cleft palate and some mobility disabilities). The program itself was appropriate; but unfortunately not everyone who was eligible for the program accessed it.

Late birth registration for children existed in both study districts and directly affected CWD's rights to free medical examinations and treatment. This issue of delayed birth registration was not mentioned at all focus group discussions and in-depth interviews, but the research team came across by chance three cases of late birth registration. All three children had severe disabilities but had not got free medical examinations and treatment just because they did not have a birth certificate. The first case was an 8 month-old boy with cerebral palsy that the team met at the People's Committee of Phu Vinh commune, Dinh Quan suburban district, Dong Nai. On that day, after finishing the last focus group discussion of the morning, the research team was about to visit a family with CWD when a mother suddenly called after us: "Aunts, help to examine my kid ". After a short conversation, we knew that the mother was from a nearby commune and had heard about the delegation and brought her kid over for examination. The mother sadly told: *"my kid gets 8 months old already. He is paralytic and canot do anything; however, health care workers at the commune health center did not agree to examine him as he has not been registered for a birth certificate yet"*. The second case was a girl in Gia Canh, Dinh Quan, Dong Nai, whose behavior was similar to a dog's. She is 9 years old but had only just got her birth certificate a few days earlier. She had never received any free medical examinations and treatment. The third case was a 14 year-old girl in Khanh Hoa commune, Chau

Phu district, An Giang. She suffered from cerebral palsy, could not walk by herself nor look after herself. She had also only got her birth certificate a few days ago. When the delegation came, her mother showed us the birth certificate as she was so happy to have it. This girl had never got the benefits from any policy, even free medical examinations and treatment. These were cases that the research team came across and we can assume there must be other CWD without birth certificates yet and so a missing out on free medical services.

All above-mentioned families and many other parents with CWD really did not understand about CWD's rights and their own rights to ask for benefits. Regrettably, local authorities had not worked out the best way of informing each household, especially ones with CWD, of policies.

5.4. Education for CWD

Parents' attitudes toward CWD's learning

Parents in the two researched provinces were generally supportive of their disabled children's studies, but often hesitant and concerned in selecting the most suitable type of education for their children. Most of the parents wished that their children would be given the chance to study with the hope that in the future, they would be literate and learn a vocation to earn their living. Nevertheless, the very severity and form of the children' disabilities pushed the parents into a "dilemma" when considering whether to send them to inclusive education, exclusive schools, social protection centers or home-schooling. The fact that exclusive schools for CWD and social protection centers were located far away (not located in the two researched districts), was really concerning to parents:

> *I must send my kid there [inclusive school] and ask for help from the female teacher as my kid is unlike others. Before enrolling, I had to go to see the female teacher for helps, wishing her to pay more attention to my kid as my kid is not as normal as other peers*
>
> (One mother in Gia Canh, Dong Nai with a disabled kid who was learning at a primary school. She was crying while talking).

When considering sending their CWD to exclusive schools two opposite trains of thought emerged from the parents: those that were concerned and those that were comfortable with the idea. Parents of children with severe intellectual retardation, cerebral palsy, and behavioral disorders were commonly worried as their children did not have ability to look after themselves they were concerned that females teachers would not have much time to care for their children; worried that their children would be bullied by friends of the same age; and that they did not earn enough money to cover school fees (as the majority of them were very poor). Parents of children with slighter impairments that were not related to the brain did not show concern about their children learning at inclusive schools. More importantly, they believed that schools would create favorable conditions for their children and that their children would learn and acquire knowledge well (as their children's brains still developed normally). That was the truth that many parents with disabled children who learnt at inclusive schools shared:

> *Before going to school, they were less knowledgeable. After learning, they became more obedient, knowledgeable and conscious. When being bullied by their friends, they ignored. They all were eager to learn and every day, they looked forward to learning hours and they all did know how to keep their personal hygiene ''how to wear clothes on their own", "got aware of other people looking at them and disparaging them".*
>
> (The focus group discussion with the parents in Gia Canh, Dong Nai, who had disabled children learning at primary school).

However in reality many parents, particularly those with severely disabled children, wished their children to learn at specialized schools. For them that was the world of CWD, therefore, they would not be bullied by non-disabled children and cared for more attentively:

> *We all expect our kids to go to schools for CWD only so that our kids will not be bullied, criticized, and they will not feel self-pity. They will be cared and taught better, too.*
>
> (The focus group discussion with the parents in Gia Canh, Dong Nai, who had disabled children learning at primary and secondary schools)

While such types of specialized schools for CWD were out of reach, most of the parents with severely disabled children (intellectual impairment, inability to acquire knowledge, cerebral palsy - not able to walk or take self-care, behavioral disorders/epilepsy) tended to keep their children at home for convenience of care. For them, that was the last resort after several unsuccessful efforts of treatment for their children:

> *As parents, we must care for our kids; we must not leave our kids, to tell the truth that I feel too hopeless. I know my kid's disease is incurable. I will feed my kid once he is still alive. I just hope he will not catch common diseases like flu or fever of something"*
>
> (One mother in Gia Canh, Dinh Quan with a 16 year-old kid who had been suffering from cerebral palsy).

Barriers arising from CWD and their families

Although most of parents supported their children going to school, the children's severe disabilities; distance from home to schools; their poverty and need to earn money; their worries that the children would suffer from deprivation at schools; lack of knowledge about learning opportunities; and lack of beliefs in their children's ability to learn were all typical barriers to CWD so they were not given the chance to go to school or had to leave school to help their families.

The kids' severe disabilities and abnormal pathology made their parents lose beliefs in their ability to learn or keep them at home to avoid their safety-related risks.

In this research most of CWD who did not go to school belonged to one of the following three groups: the group of severely intellectually impaired children who could not communicate; the group of children with behavioral disorders who could be a danger to other people or to themselves; the group that could not look after themselves (severe cerebral palsy or epilepsy with seizures of high frequency).

This pattern was homogeneous in both researched provinces, however, the number of CWD in this group was much larger in Dong Nai (according to the residents here, this was the place that was spread with dioxin). With such CWD, although their parents really wanted their children to become literate or care for themselves, it seemed to take all their effort just to remain positive in outlook.

They had truly lost belief in their children's ability to learn:

> *At times, he had a fit of epilepsy, he insulted impersonally, even insulted his mom but he was not aware of it. His friends and teacher got scared of him. My kid had a bad memory, you see: he could not even remember letter 'A' although he had learnt it for several months. He even hit his female teacher so my family decided to make him drop out of school*
>
> (One mom in Gia Canh commune, Dinh Quan, Dong Nai, whose kid was 13 years old. The kid dropped out of school due to behavioral disorders).

There were also CWD who were capable of learning at school, but deprived of the chance as their families about their safety because of their abnormal health conditions. They kept their children at home to ensure their safety instead of letting them go to school. For instance, a 15 year-old girl in Gia

Canh, Dinh Quan, Dong Nai, left school during second grade due to high-frequency epilepsy (5-6 seizures per day). She had been learning from kindergarten to second grade.

One day, while learning, she got a fit of convulsions and then fainted. After regaining consciousness, she developed a headache and dizziness. Doctors told her she had epilepsy. Gradually the epileptic fits more frequent, at times, 5-6 fits a day. Worries about her safety meant her mother let her drop out of school and restricted her to going to neighbors' houses. At the time of this research she could communicate well, look after herself, and draw nice pictures although she had never been taught to draw.

Another child, a 14 year-old boy in Binh My, Chau Phu, An Giang with a paralyzed right arm and a patch of soft skull bone of about 5-7 cm in diameter was also deprived of the chance of attending school. He looked cute, could communicate well and follow adults' instructions. His family let him off school as they were concerned about his safety each time he was hit and teased by other children, especially when they touched or pressed on his soft skull bone:

> *He is my paternal grandson. He is 14 years old this year already but he only stays at home. He has the problem of soft skull bone (There is a very soft patch on his head with a diameter of around 5-7cm), so other kids often teased him and pressed that part. One day, it got swollen, which was very dangerous.*
>
> (The paternal grandmother of a kid in Binh My, Chau Phu, An Giang,
> whose arm was paralyzed and had soft skull bone)

Poverty generally prevents children from continuing school to help their parents

This reason was very common in the two researched districts because the households here main incomes was from going into other people's services like tilling the fields, producing bricks, working as masons, or catching shrimps, crabs and fish for money. Their average daily per-capita income, however, stood at only about 30-50,000 dongs (including expenditure on foods). In addition to this their income was not regular: "they earned some days, but other days, they could not". Given the fact that " more labor yields more money", many parents made their children drop out of school to work with them for money or to do domestic chores which freed up the parents time so they could go into other people's services.

This way, parents would not have to pay school fees for their children either. So the children lost out on the chance to go to school. For instance, a 14 year-old boy in Binh Chanh, Chau Phu, An Giang, who had defect in his left eye (poor vision), finished 6th grade and stopped learning as his family did not have money to pay his school fees. He stayed at home to help his parents. He talked about his quitting school with sad facial expression: *"I want to go to school but was told by my mom that my family was poor, mom did not have money for me to continue learning and that I would have chances to resume learning when she had money… I stayed at home to help her with housework like doing laundry, tidying up the house, feeding my younger siblings so that mom and dad could go to work"*.

Right after the talk with him, the research team continued an in-depth conversation with his mother and learnt that his family wanted him to go to school. In this diligent mother truly believed that children who got an adequate education were successful. However, she did not have money to pay for school fees, which was the reason for making her son leave school:

> *I also wish to let him continue learning. He is diligent and can learn, but I do not have money for him to learn. It is not easy for me to earn my daily bread, let alone school fees. I used to raise fishes; however, fishes died all so my family fell deeply into debts. We did not have money to send him to have his eyes cured or pay for school fees. Each time his teacher asked about school fees, he played truant for some days... He had been learning and playing truant again and again for six successive years. Now he drops out of school. I still try so when having money, I will send him to school again. I told him so. I have been striving much but I do not have money yet, you know.*

Long distances from home to school were also a barrier that could not easily be lifted for severe CWD, especially when their parents 'enter the season of hired labor'

This barrier was obvious in the two researched districts because of the sparsely populated households, especially with those tilling the fields on hills. Only during the leisure period after harvest time, the parents could take their children to school. During the season of hired labor or when they were offered additional work by neighbors, the parents would give priority to going into other people's services to earn money rather than taking their children to school:

> *Home economics of the people here is very hard. They have to go into other people's services on a seasonal basis (sugar cane and cashew nut seasons). When the seasons come, they have to get up early and come back home late as they are busy at work. It is very hard even if the parents want to take their kids to school as the school is located very far away (some kilometers sometimes).*
>
> (Health care and child protection officer in Gia Canh commune, Dong Nai)

Even with quite grown-up children (learning at secondary schools or high schools), long distances remained the biggest barrier. Together with bad home economic conditions, these long distances, strengthened parents' decisions to let the children leave school:

> *I should have learnt at 10th grade now. I sat for an entrance examination to high school, however, the school is too far away from home, over 12 kilometers away. I have not got a bicycle yet. My parents do not have money to buy one. I love learning a lot but had to leave school and stay at home to help my parents… I understand my parents' circumstance so I do not hold them responsible for this. I am glad as I can help my parents with housework*
>
> (17 year-old girl in Khanh Hoa commune, Chau Phu, An Giang, who left school and had a defect in her left arm due to a burn from boiling water)

There were some exceptional CWD who were able to go to schools despite the barrier of distance thanks to support from others. The support included: "friends-helping-friends" whereby a non-disabled kid took a CWD to school; CWD being taken to school by their relatives; or at times CWD own efforts. Somewhere in the two researched provinces, non-disabled children carried CWD on their backs or by bicycle to school. There were relatives, uncles and aunts, who took a break from their daily work to take CWD to school while their parents were too busy working as hired labor. There were also CWD who ignored barriers of diseases and families' poverty and insisted on going to school although they often arrived at school late. Regrettably, only few CWD got such support and these were usually the little children (elementary and secondary schools). There were just a couple of such cases at the most in each commune (according to primary inclusive teachers in Khanh Hoa commune, Chau Phu, An Giang and parents of non-disabled children in Gia Canh commune, Dong Nai). The following quotations illustrate this point:

Some CWD did love learning a lot. Sometimes, they were 1 hour late for school but they tried to go to school and insisted their teachers to let them in to the class. There were even kids who were late for term exams. They insisted their female teachers to let them in for the exams.
(The focus group discussion with secondary teachers in Khanh Hoa, An Giang)

There was a kid who suffered from defect in legs and could not go to school by himself. However, he was taken to school by his friends or aunts or uncles when he was at primary and secondary schools. He caught buses to school when getting older and having to go to school far away but did not get any help from other people.
(The focus group discussion with secondary teachers in Khanh Hoa, An Giang)

There was a kid with defect in legs, however, she was very good at learning. She was carried to school on her friends' backs during her learning period. She was very good at writing essays and loved by her peers
(The focus group discussion with secondary teachers in Khanh Hoa, An Giang).

Love and empty feelings when away from kids discouraged the parents to send their kids to exclusive schools or social protection centers

Many parents wanted their disabled children (often severe cases) to be cared for and taught at specialized units (specialized schools and social protection centers), however, their love for them and empty feelings when away from them along with constant worries about the childrens' health conditions prevented them from carrying out their wish. For instance, a 16 year-old child with intellectual impairment, unable to speak or to look after itself was sent to a social protection center in Bien Hoa (the mother could not remember the exact name of the center). After two months, the mother found the child had got much weaker so she decided to bring him home:

If I had not brought him back home, he should have died. He was not cared for as well as at home. I fed him with many meals a day, with little per meal. He was given with three meals per day there with foods cooked by them. For me, if he can not eat rice or sticky rice, I will give him noodle food instead…
(One mom in Gia Canh, Dong Nai with a child who suffered
from intellectual impairment and could not take care of himself)

In addition to that mother who used to send her kid to a social protection center, there were many other parents with children who suffered from similar, severe disabilities (maybe with different types of disabilities). In the two researched districts, many of the parents were not really willing to send their children to such units. A simple reason lay in the fact that they *"love their kids as they are already disadvantageous than their friends, moreover, they lack their parents' cares. I will miss my kid if she goes to such units"*. Such accounts were repeated in many discussions with the parents who had severely disabled children in both researched districts.

The lack of information about education and care services for CWD's interests also contributed to deprived CWD's learning opportunities

The lack of information about interests, caring, education units for CWD was common in both provinces. Most of the parents and children who participated in focus group discussions were ill informed about the education opportunities for CWD. Many of them understood vaguely or 'heard somebody talking' about those units. What they heard was as superficial as *"there seems to be a school of something for CWD at the provincial level"*.

A few parents of severely disabled children were able to go long distances to educational facilities for CWD to seek advice, but they often returned with disappointment as their children's disabilities were severe disabilities and their children did not fall into the list of beneficiaries of social welfares. They were commonly officers in the commune/hamlet or had relatives working in the provincial authoritative bodies and had a thorough knowledge the CWD's situation. That was the case of one father in Gia Canh, Dong Nai who had 3 children, one of whom suffered from cerebral palsy and could not walk. The father was the head of a hamlet and took initiatives to ask about opportunities of care for his child at Bien Hoa CWD and orphan nurturing center. Many other parents had never asked or not known about where to seek advice, so they remained at home with their compassion: *"I wonder what difficulties would appear when my kid got there. Surely my kid would suffer from misery. If so, we had better keep him at home with parents"* (The focus group discussion with the parents in Gia Canh, Dong Nai, who had disabled children).

There were exceptional cases; however when both parents were intellectuals, educated and had a broad network of relations and contacts, even with relatives working in the health sector, but they eventually ended up with a dilemma where to send the child to. That was the case of a family with a 13 year-old girl in An Chay town, Chau Thanh, An Giang, who suffered from cerebral palsy (see Case Study Number III). The family's lack of awareness of the information had a high price tag as in meant the girl had been out of school for a long period of time (from the age of 6 to 12).

Inclusive education

While inclusive education was regarded as a common measure that promised to give education and inclusion opportunities to most of CWD, in reality, it was almost the opposite that occurred as most of CWD had never gone to school or had left school before getting to the school-leaving age. This situation was particularly obvious in Dong Nai (see *for details in the section of social function-based classification of CWD*). The CWD that joined in inclusive education were mainly those who had mobility disabilities or lack of a body part. Other types of disabilities like hearing impairment, visual impairment, behavioral disorders and intellectual impairment made up a small percentage. Besides, the quality of inclusive education was limited because: teachers not well-trained and or fully equipped with technical assistance for integration teaching; lack of supportive and rehabilitation facilities; lack of documents and quality assessment system for CWD; lack of entertainment, enjoyable activities, especially physical education for CWD; the incentive regime for integration teachers remaining too modest; and absence of a successful model of inclusive education. Additionally, a remarkable number of CWD dropped out of school for various reasons: helping their parents to earn income or do domestic chores; long distances from home to school; hard economic conditions (lack of money to pay for school fees); and more importantly, the community and parents' acceptance of children' working as a partial remedy to their families' inherent poverty.

Inclusive teachers had not been fully prepared for methods and conditions to teach and deal with different types of disabilities, especially for CWD of intellectual impairment, behavioral disorders and unexpected diseases

Most of integration schools (primary and secondary) did not have teachers majoring in disabilities studies. Those schools prepared for this by sending some senior administers/teachers (of schools and grades) to learn about teaching methods for integration. Afterwards they would come back to share what they learnt with their colleagues. However, training contents mainly focused on aspects related to morals and attitudes toward CWD, but rarely on teaching methods for CWD in a concrete way (like preparing lesson plans, assessing CWD, or teaching skills for each type of disabilities). The teachers particularly faced challenges when working with CWD with intellectual impairment and behavioral disorders as they were not adequately prepared to teach these groups:

> *We have to re-teach again and again for kids with intellectual impairment to make them understand. However, they forget all the next day. We do not know about any other method to teach such kids, we just follow ways that we can think of*
> (Secondary teachers for integration in Khanh Hoa commune, Chau Phu, An Giang)
>
> *Almost all teachers at integration schools are not experienced at approaching to understand CWD's disease conditions. Many kids with epilepsy often faint down, others often scream so schools must send them back to their families for cares... Those kids will not usually come back to school again, the issue lies in the fact that there is no policy made by communes to help those CWD to resume learning...*
> (In-depth interview with the Vice Chairman of Gia Canh
> commune's People's Committee, Dong Nai)

Preparation for lesson plans and assessments of CWD's abilities had not been synchronously implemented among schools and within each school

Teachers found themselves puzzled as they were preparing lesson plans and assessing progress made by each disabled child in each class. Ironically, they did not have concrete instructive documents nor timely support from seniors and colleagues in this aspect:

> *We have made lesson plans for CWD based on our experience. We prepare general lesson plans for non-disabled kids and save a separate part for CWD. However, this is our own experience. There are not general instructions given to us from higher level, nor are there references at all... Besides, we encounter difficulties in assessing their progress. For instance, both non-disabled and CWD sit for end-term or end-school year examinations with similar exam questions whereas with tests during the term, they deal with different questions given out by us. Everything should be checked and different for CWD*
> (According to the group of primary school's teachers
> for integration in Phu Vinh, Dong Nai)

Teaching methods for CWD were not standardized yet, but mainly based on each teacher's experience and enthusiasm

According to all focus group discussions with teachers of integration at primary and secondary schools, however, the most common supportive forms for CWD (out of main lessons) in both provinces were: the teachers assigned good pupils to give further teaching to CWD under the teachers' supervision and monitoring; the teachers gave private lessons to CWD during breaks; or gave extra-classes (free of charge) on one afternoon or one day of the week or at weekends. All these approaches were individual teacher's ideas. They were not systematic or part of the education sector's general instructions. Therefore, many teachers proposed the education sector encourage extra-class mentoring for CWD and apply incentive policies for teachers' extra-class mentoring hours.

Incentives were not proportionate to inclusive teachers' effort and expectations

Inclusive teachers did not receive any incentive other than a reduced number of pupils for each class (for each CWD, the numbers of pupils in each class would be reduced by 3-5 pupils depending on each school). Meanwhile, they had to spend much more time preparing lesson plans for disabled pupils. Many of them even spent time giving further teaching tor CWD at breaks or teaching them more at weekends, too. Teachers in at least 3 focus groups in both provinces repeatedly complained that integrating CWD even reduced their classes' "achievements":

As usual when there is no presence of CWD, we focus on teaching good pupils to turn them into brilliant pupils. When with presence of CWD, we do not have time left to improve good pupils any longer. Thus, the number of good pupils gets smaller.
(The rector of a primary school in Phu Vinh commune, Dong Nai)

For instance, if the class is ranked as a brilliant class, it shall be dropped down to good rank, as with CWD in classes, the teachers will have to spend more time teaching them in each lesson
(The focus group discussion with primary teachers in Khanh Hoa, An Giang*)*

Although not satisfied with incentive policies, many teachers had been working hard only because of "heart and passion" for the job and love for CWD. Among them was a female teacher at Phu Vinh primary school in Dong Nai. She accepted a pupil with intellectual impairment – for all successive four years of primary school. This pupil had never talked with anybody, even his female and male teachers before becoming her pupil. Since the time he was accepted (from 5th grade) until he finished 8th grade, after each lesson or break, the teacher approached him and talked softly with him. During breaks, she often came to him to check and correct his work. On many Saturdays and Sundays, she fetched him from home to school to give him extra lessons without charging any fee. Gradually he became fond of talking with people around him. He had also made remarkable school progress. The school commended both the teacher and the pupil on his learning achievements and her responsibilities for teaching CWD. There was a similar example in Khanh Hoa, An Giang. One primary female teacher taught one pupil with intellectual impairment during all breaks and rests after lunch when she should have rested. She did not need any encouragement nor any incentive policy for whatever she had done. For her, everything was because of "her heart for teaching and love for CWD". However, in her colleagues' eyes, she was a shining example. When being asked about good examples of teaching CWD, all her colleagues at the focus group discussion in Khanh Hoa commune, Chau Phu, mentioned her name in chorus. One of them excitedly told the researcher about what she had done while she went red in her face and smiled bashfully.

Schools all made efforts to promote education for CWD, however, they often did independently from other community-based education promotion activities, and thus commonly not guaranteeing success, particularly in encouraging CWD back to studies after a school drop

Many schools offered gifts, bonuses, learning tools, and incentive to study (exemption from and reduction of school fees) for CWD who were learning at their schools. As for those CWD who left school or did not regularly go to school, the schools sent teachers to each household to encourage the parents to re-enroll the CWD. Such efforts, however, were often ineffective. Key reasons lay in the poverty of CWD's families which drove them to give priority to other people's services and earning money than sending their children back to school: *"Many times, female teachers at schools came to me, asking me to take my kid to school again. However, I was busy going into other people's services, I did not pay attention to his studies any more."* (The focus group with parents having children who did not go to school - in Binh Chanh commune, An Giang).

The lack of entertainment and recreational services for CWD at schools partly restricts their integration

According to most teachers and CWD inclusive schools did not have infrastructures, practicing tools or exclusive games for CWD to help them integrate into school life. Popular games at inclusive schools tend to incline towards mobility and team work like soccer, shuttle cock, marbles, skipping… Regrettably, children with severe mobility disabilities (like legless, armless, or cerebral palsy) could not play such games. Therefore, during breaks or physical training, severe CWD often sit still, watching other children playing or sit in classroom:

> *I do not like games with friends as my legs are paralyzed. So I have to sit on a wheelchair. Each time, friends enjoy their time; I just look at them or sit in the class. My younger sister [learning at the same class] takes me out on the wheelchair for me to watch them playing.*
> *(*A kid with mobility disabilities, learning at 4th grade in Phu Vinh, Dong Nai)

Children with intellectual impairment are sometimes rejected from games due to their lack of skills or insufficient motivation to participation. For instance, one child with intellectual impairment, 15 years old, learning at 4th grade in Phu Vinh, Dong Nai, kept sitting in the classroom during breaks as he could not join in any games. Nobody encouraged him or guided him to play the game.

Social protection centers

The number of social protection centers remained modest and served a small portion of severely disabled children in the list of beneficiaries. There were about 20 social protection centers in Dong Nai, bringing up over 3,000 children, meeting only 1/7 of the actual numbers (according to leaders of the provincial social protection branches). An Giang had only one social protection center, nurturing around 20 children whereas the number of CWD in the community that needed the service goes far beyond that limit. (See further in the part of social function-based classification).

Social protection centers only focused on nurturing activities, but paid little attention to teaching literacy, vocations and living skills for CWD

The Bien Hoa center that nurtured CWD and orphans was an exceptional case of nurturing models. There CWD were nurtured, given health care, and taught literacy, vocations, and living skills (communication). They also had a chance to develop their aptitudes (music and painting). However, the number of children enjoying this opportunity remained only about 200 in the entire the province. The center has experienced significant achievements in improving life for CWD there. A child who suffered from autism and did not communicate with anyone at home was a typical example. After a year at this center, he became able to communicate normally and was confident enough to stand up and sing a song when the research team visited. There were children who could not learn math but had ability to play musical instruments and draw pictures. These successes meant CWD here got chances to develop their aptitudes. CWD here also got chances to learn vocations depending on their abilities like knitting, sewing, household arts, hairdressing and carpentry. Some managed to apply for jobs with the support from the center's administration and their families. Still, this number was very small. The school also tried to create a connection between vocational training and job seeking for CWD, however, opportunities for employment were usually unstable and such effort rarely became a success.

Common difficulties and challenges in those centers lied in lack of material facilities, teaching and rehabilitation equipment for CWD, especially lack of skills of cares for severely disabled kids

The reason was children here suffered from several types of severe disabilities, which required the carers to be both committed and skillful in dealing with each different type of disabilities. Most of officers here, however, did their work based on their experience and got accustomed to it while getting little or no technical assistance from outside. Even with Bien Hoa nurturing center - an entity with a long history of achievements and experience, was facing a series of challenges: officers' lack of teaching and rehabilitation skills for CWD; absence of instructive documents about caring and teaching children; absence of a mechanism of CWD's assessment and technical supervision and support (mainly based on experience); unstable connections of vocation teaching and employment for CWD.

Besides, CWD at social protection centers often lacked opportunities for exchanges and integration into the outside community

Most of social protection centers did not hold integration and entertaining activities to connect CWD with their outside societies. This meant most of CWD who went to those centers would stay there until old age if they did not have opportunities to integrate during their development process (e.g., attended vocation training or learnt at integration classes, or succeeded in finding a job). Bien Hoa CWD and orphan nurturing center was much more advanced than other centers with respects of amusement, recreational, and integration for CWD. There was a precinct large enough for 200 children to play at the same time in this center. The center had equipment for them to play with (like horse toys, wheels etc), and classrooms and rehabilitation rooms contained modern equipment relevant for disabilities of all kinds. Particularly, most of the classrooms there were decorated with “friendly classes”. Many pictures and children’s creations were hung on the classrooms’ walls, creating a jubilant, fresh and friendly atmosphere. Besides, the center occasionally organized for children to go on vacation, beaches, or exchanges with individuals, organizations, and visiting schools. Nevertheless, the center managed to have too few opportunities for CWD to visit and mix with outside communities.

Specialized education (exclusive education)

Specialized schools currently stayed on a modest scale and served a small portion of CWD in need (mainly hearing and visual impairments and some children with intellectual impairment)

An Giang had one specialized school with a capacity to accommodate about 700 children. This school accepted children with hearing and visual impairment. Dong Nai also had one school with a full enrollment of 200 children. Besides hearing and visual impaired children, the school also accepted some children with intellectual impairment. The number of CWD in both schools, as such, was too small compared to real demands (see further in the part of CWD classification).

Both specialized schools had a decent infrastructure with sufficient learning, rehabilitation, entertainment, and vocational training facilities for CWD’s demands

There were particular areas for meals, accommodation, amusement, learning and vocational training for children. Within the school’s precinct and in-between accommodation rooms, lie areas for amusement, sports or vocational training and kid-product displays for children. Vocational training was also diversified and relevant with CWD’ preference and abilities like knitting, household arts, hair cutting, even massage. Audiovisual equipment was diversified, too. There were enough hearing-aids for hearing impaired children; embossed words (Braille), audio and video disks, and supportive Internet-reading software for visual impaired children (i.e., NDC and JAW software). Both of these software packages had sound-generating devices which enabled children with visual impairment to type and read documents on computer or access on-line materials. Besides, the two schools also provided rehabilitating exercises for children. Rehabilitation lessons and physical training in general are included in their syllabus.

Common challenges for both schools lay in making replacement assessment, composing syllabus and coping with different defects and diseases; lack of instructive manuals; lack of technical supervision and support from higher levels; shortages of opportunities for CWD to really integrate into the community; and shortage of opportunities for vocational training, and employment for CWD after graduation.

Placement assessment has not been standardized yet

Teachers commonly used their own experience to assess CWD’s awareness and their ability to learn through talking with their parents, rather than using any concrete criteria, guidance or collaborating with other colleagues in doing so. This independent process might generate bias or errors in selecting CWD.

> *We organize to recruit CWD once a year. Each teacher shall discuss with CWD's parents about their abilities. Kids will be accepted if possible. We base on our own experience only, but not any concrete criteria.*
>
> (FG with the teachers at Bien Hoa exclusive school).

The schools faced challenges in composing syllabuses, amending teaching methods and assessing teaching outcomes due to the lack of instructive documents and timely technical supervision and support

Many teachers at these two schools have been trained about defects, but most of them teach based on their own experience. They sometimes exchange information with one another and get supports from their colleagues (at meetings and seminars) but rarely get technical assistance for lesson plans' designs and methodology amended from higher levels. Moreover, inclusive schools still applied the pupil assessment form issued by Ministry of Education to assess CWD's progress, but did not have a separate assessment tool for CWD or for each type of disabilities.

The schools provide amusement and recreational activities for CWD, however, they do not promote activities to include them in outside societies

There are big playgrounds at two schools which may be used for various games, including soccer and swimming. There is a swimming pool in Dong Nai's exclusive school. Although large, the playground there is in concrete and restricted by the glass windows of the surrounding houses, and thus not relevant for CWD to play games that require a lot of moves like soccer, running, and jumping. An Giang's school does not encounter this problem as most of the playground is covered with grass. Games at these two exclusive schools are diversified, mainly with soccer, table tennis, badminton, skipping, and badminton. The exclusive school in An Giang also provides Chinese chess and cards for children who could not play or were not fond of the other games.

Besides the above daily games, the two schools sometimes invited individuals, organizations or schools with non-disabled children to come over to play and mix with the school children. Still, there have been few of such chances (a few times a year) while the children commonly were passive waiting for others to come over, but not vice versa.

The schools also provide counseling services for early intervention for those parents who are interested in, however, they do it for form's sake only, but do not take initiatives to deliver these services to the majority of people in need

In fact, the counseling service for early intervention is a small program, integrated during enrolments or upon parents' request, but not systematically:

> *Sometimes, we give counseling to some parents with under-school-aged CWD. They take their kids for medical check-ups at hospitals and know their kids are disabled. They go to our schools to consult for measures. We just guide them to monitor and teach their kids at home to get prepared for 1st grade.*
>
> (The teacher group at Bien Hoa CWD nurturing center)

Few parents know about this service as the schools have not tried to promote it to community in general. Neither have they had a mechanism of monitoring, supervising, and supporting parents with such demands. Therefore, parents might come one time and never go back for further advice. No connection, hence, existed between the schools and parents.

The two schools pay attention to vocational training for CWD, however, meet difficulties in finding jobs for them after graduation

Both schools offer vocational training upon the market's demands and CWD's strengths. Common vocations include: knitting, household arts, hair cutting, and massage. However, their sub-standard products and restricted opportunities to work at factories or manufacturing enterprises make the above-mentioned vocational efforts almost for form's sake. (See more details under the section of employment opportunities).

Education in the community

CWD groups in the community (not the above groups) rarely had the chance to access education. With CWD who are about to enter school, their families and kindergartens play important roles in preparing them for school. It is not easy all the time, however, because the parents lack knowledge about educating children while kindergarten teachers often hesitate to accept them in their classes fearing potential difficulties caused by the children's disabilities. Those CWD that dropped out of school do not have a chance to learn anything else. This group often "teaches themselves" through T.V, radio, and newspapers at the most, or through playing creative games like drawing. No pattern of cares and education support ever existed for the severely disabled groups (especially those with cerebral palsy and those unable to care for themselves; and those with intellectual impairment, and with behavioral disorders). Parents think about sending their children to social protection centers in the province but often withdraw their intention due to the long distances from home; their loves for the children; poor economic conditions; and the lack of knowledge on CWD's interests, opportunities and difficulties when entering those facilities.

Parents and pre-school teachers are main instructors for CWD who are about to enter 1st grade, but it is not always easy due to parents' insufficient education and hesitance of the pre-school teachers

The majority of parents with school-aged CWD age are very interested in their children's studies and are very keen for the chance for their children to go to school. Kindergarten is the first place they think of, nevertheless, the very disabilities of their children make them hesitate sending their children there:

> *I am not sure if my kid will be accepted or not, cared for carefully or not. My child suffered from seizures so I am worried if somebody will take care of her and that if it is a pity if she is sent there...*
>
> *The kindergarten accepted my kid when not knowing about her innate defect. After knowing her status, the female teacher did not want to care for her because they were concerned about some incidents that might happen to them. The parents had to take responsible for whatever happenings to their kids so that the kids could continue learning there...*
>
> (FG with parents of 5-6 year-old CWD
> who are prepared for school, Gia Canh, Dong Nai)

The above statements show that children with slight disabilities, like non-disabled children, can go to kindergartens, while for children with severe disabilities, the situation is much more serious. As in Case Study III (in An Chay town, Chau Thanh, An Giang), those concerns become more obvious when the mother repeatedly failed in seeking an enrolment opportunity for her daughter. She ended up with sending her child to a kindergarten managed by her close friend. The child got the chance to learn and prepare for 1st grade. Unfortunately, the mother's friend had to reject the child after some months just because the child could not go to toilet by herself (as she suffers from a cerebral palsy). The mother had to take care of and teach her child at home. Luckily, the mother is a civil servant at a high school so she could teach her child to learn. The child also learnt some math and writing from volunteers at the hospital.

Those children who dropped school lose almost all chance for further studies

Most CWD dropped school due to their severe disabilities or families' poverty. They almost always lost opportunities for further studies in most cases. It is obvious that children with intellectual impairment may have to leave school, but really not fair for those children who were able to learn but tended to accept the "dropping out" naturally and were even satisfied with the decision due to their circumstances.

> *I want to learn more but feel contented and glad as I left school and stay at home to help my parents*
>
> (One child with defects in her arms, in Khanh Hoa commune An Giang).

Ironically, not a single CWD who ever left school in this study wanted to continue learning in the orthodox education system, however, a few wished to learn some vocation and go to work to earn money later:

> *I want to learn clothing (tailoring) to earn money later. I find some older girls with disabilities working as clothes makers at a factory in the province, but I have never got any chance to learn it yet.*

Even such a simple dream can hardly be realised as the instable vocational training and employment markets do not always weigh in their favour. Both study districts are far away from the provincial center –where there are many production facilities or garment enterprises. Moreover, even if they live in the center, it is not easy for them to attend vocational training or find a suitable job as it depends on the strictness in quality standards, enterprise owners' cooperative attitudes, and the market's demands for products and their skills (See further in the part with opportunities for vocational guidance and employment).

Families serve as the unique providers of care and education for the severely disabled group

Besides some social protection centers (not located in the two study districts), there is not any pattern of care and education for the severely disabled group. Such children are cared for and educated at home. Caring and education levels for this group depend on each family's context. Normally CWD from families with better economic conditions are more attentively cared for and even taught more about activities related to their intellectual level (if the children' cognitive ability allow them to learn) as they often have somebody available at home. For instance, a girl in Gia Canh, Dong Nai, had to drop out of school due to her high-frequency epilepsy. Her parents buy papers and pen and learning equipment for her to use. In that context, she taught herself drawing and became able to draw very nice and lively pictures about her life (like the picture of her feeding chickens and a picture of a family gathering). However, with families where parents are very busy without anybody to care for CWD, the children have to either stay at home or go to neighbors'. In many cases, CWD can not walk so they have to stay at home alone, moving about only within a limited area arranged by their parents. For example, one 14 year-old girl in Khanh Hoa commune with cerebral palsy can not walk nor take self-care. Her parents are busy the whole day working, so they have to leave her at home alone in a clean and well-ventilated room. The neighbors occasionally drop in to see her. Otherwise, her parents come back home at noon and in the evenings to feed her and bathe her. With such children, parents do not believe in their ability to learn so they bring them up with of the outlook that it was fate that meant they had a CWD.

Barriers at the community level

There still exist various barriers within communities to create equal opportunities for CWD to go to school. These include the lack of an effective survey and education counseling system for CWD; the lack of collaboration among authorities, sectors and unions in promoting and encouraging CWD to go school; the lack of support in implementing policies for CWD; and the community's acceptance of CWD's working.

First, there is a lack of an effective survey, screening and counseling system to prepare CWD for 1st grade. At present, CWD's families take initiatives to do whatever they can to seek opportunities for their disabled children to learn in the absence of any system of education counseling for CWD. Although there are social protection centers, and inclusive and exclusive schools in both provinces, in reality, few parents know about them. Most of them are very vague about CWD's rights and opportunities to learn at those facilities. Besides, some CWD with the ability to learn are ignored. These included the 9 year-old girl with the habits of a dog in Gia Canh commune, Dong Nai, or the 12 year-old girl in An Chay town, Chau Thanh, An Giang with cerebral palsy. The former girl has never been mobilized to go to school although she is 9 years old (See for details in Case Study I). The latter girl was denied school entrance just because she could not go to toilet herself and because she was too old for school (Case Study III). Over a period of six years her mother has repeatedly asked about learning opportunities for her but without success (from the time she was 6 up to now when she is 12).

Secondly, there is insufficient multi-disciplinary collaboration in communications and mobilization to families with disabled children regarding education promotion. At present, the education sector plays a key role in encouraging families with disabled children to take their children to school. This is not enough as it is likely to miss out children. Most of parents with disabled children who dropped out of school said at FGs that teachers often came to their houses to encourage them to re-send their children to school but they rarely saw hamlet/ commune or sectors, union's cadres do so. This means the authorities at the two study districts have not really jumped on the bandwagon to carry out a survey on the list of CWD at school age. This explains why some children are not given the chances to go to school as they reach school age and had the ability to learn.

Thirdly, it is a partial measure for poor families to let their children go to work, which created more motivations for CWD to drop out of school. It is due to the simple reason that the inhabitants in the two study districts mainly rely on farming laboring for their livelihood. Families with CWD are often poor, even have to "struggle for their living", so they can not care for their children's' studies. In such contexts, it is more acceptable for CWD like a child over the age of 10 to till the fields or help his parents with housework than to go to school: "I earn 40,000 dongs a day. It is better than sending him to school" (The mother in Binh Thuy, An Giang with a 14 year-old kid with slight mobility disabilities).

The lack of a consulting and supportive system for the implementation of education policies for poor families with disabled children also contributed to the school drop out rate. Some families are very poor (as verified by the communal People's Committee), but their expired poverty certificates have not been extended yet. Obviously this means their children will not be entitled to enjoy school fee exemption or reduction. Some children had to drop school to help their parents (due to having no money to pay school fees). For example, a mother in Binh My commune, Chau Phu, An Giang, who has a 14 year-old child with defected left eye, made her son leave school just because her son did not continue to get school fee exemption or reduction. In reality, this family is poor but the poverty certificate expired (it is valid for two years and needs extending every two years). The mother has not applied for its extension just because she is illiterate, but she hesitates to have it written by the hamlet or commune's cadres. This passive information seeking pattern among parents of CWD is similar to the opinions of parents with disabled and non-disabled children alike:

> *Many poor families with disabled kids are not aware of rights and policies applied for their kids. In some lucky cases, somebody who knows about their circumstances would tell the parents about their rights. Otherwise, who knows? They [parents of CWD] have never asked for the rights they have*
>
> (FG with parents of non-disabled kids in Gia Canh, Đồng Nai).

5.5. Information access

Habit of information reception

CWD's parents do not take the initiative to seek child-related information but passively accept the information from cadres in charge and grassroots personnel: health care workers, teachers, particularly village head, women union members, village health workers, and collaborators/volunteers. This pattern appeared in most of the interviews and FGs with parents, teachers and officers of all levels in this study. Some people even emphasized that: *"They will only take their kids to medical stations for check-ups when their kids suffer from severe diseases. They do not know anything about this at all"* (The vice chairman of Gia Canh commune, Dong Nai). Parents' passiveness in searching information sometimes indirectly deprived CWD's of their rights:

> *Supportive programs at communes are available sometimes, but I dare not take my kids there as I wonder whether my kids will be given with check-ups or not. As usual, only when getting notice from the hamlet, I will take them for medical check-ups*
>
> (FG with parents of disabled kids who are going to school in Binh Thuy, An Giang)

Few parents take initiatives to seek information from health care facilities, social protection centers or exclusive schools. These parents are commonly the state's cadres or have relatives near those facilities.

Information channels

Information channels for parents

The key information sharing system at the community level in the two study provinces operates through commune and village personnel such as population collaborators, village health workers, and women union members. The popularity and commonality of this channel makes it the most preferred channel for parents. In fact, those personnel can provide information on many different fields to households at hamlets, communes, or branches' meetings (particularly those of women union), even through the word-of-mouth communication. Information delivered through such events mainly focus on mothers and children's health care, family planning, business experience or policies. Regrettably, CWD-related contents seldom become a discussion theme.

> *None of the supportive delegate comes here to help our kids [CWD] because this area is remote and distant. Luckily, I get informed of the support for CWD from the hamlet head. I would not have known about the support if he had not informed.*
>
> *...I knew about medical check-ups for CWD through words of mouth as they [cadres] work near my house, otherwise, I did not know*
>
> (FG with parents of disabled children that do not go to school in Khanh Hoa, An Giang)
>
> *I know about it mainly through the hamlet's women association or words of mouth because most of the time, I go into other people's services.*
>
> (FG with parents who have 5-7 year old children in Binh Thuy, An Giang)

Television and loudspeakers are quite popular, but accessibility to these media is limited and CWD-related information conveyed through them was poor. The limited accessibility was attributable to the fact that parents must till the fields over a large area from very early morning until late so they rarely have the chance to watch T.V or listen to the radio. Moreover, the media seldom broadcast news or information about CWD, and if they do it is often about “examples of CWD that overcome difficulties” or charity examples as “sponsors”. In short, parents of CWD grasp very little related to their kids’ disease or condition and or anything of interest through such channels.

Other modes of communication like leaflets, posters, road marches or community events related to CWD have never been applied in the study area. However, occasionally, some communes celebrate CWD’s learning achievements at communal or school level, this results in those people who attend the sessions partly understanding CWD’ values and abilities.

Unfortunately, this pattern remains limited and not systematic. According to some inclusive elementary teachers in Phu Vinh commune, Dong Nai, they have only witnessed one celebration session of this type so far.

The consulting system on disabilities and CWD-related interests has not effectively operated in both provinces. Consulting services are not systematic, but to be seen to be doing something. For instance, the communication and counseling center (under the provincial social protection department) on CWD in An Giang, has recently built a decent infrastructure, but it has not actually become operational due to inadequate human resources. In the mean time, the education and health care sectors have provided counseling on CWD mainly through their networks of cadres in charge.

Unfortunately, many parents are disappointed with the quality of counseling provided by those personnel as they are either indifferent or short of relevant information. Few parents are lucky to meet responsible personnel who are caring and updated for excellent counseling (See details in the part of health care counseling system and Case Study III).

Information channels for CWD

Information channels seem more varied and relevant for CWD. T.V and radio are the two main information channels for CWD group in the community. They like watching recreational programs like sports, music and game shows the most. Few also read books, newspapers or cartoons brought home by their parents (most of them are civil servants). The inclusive education groups access more sources of information from teachers, friends, libraries (books, newspapers, tapes, and disks), T.V, loudspeakers, and radio. Some can use Internet. Child groups at exclusive schools access highly specialized information channels. Besides the main information channel from their teachers, CWD at both exclusive schools at the two study provinces can even access Internet with sound-devised software (they are taught to use Internet); documents and newspapers in Braille embossed words; books, newspapers, video and audio disks, and television channels.

Noticeably, some programs and television channels have recently used “notation language” to increase the accessibility for hearing impaired people, including hearing impaired children. The two channels that the study team knows about (through exchanges with the teachers at Bien Hoa exclusive school) are HTV7 and O2 TV. Notations for hearing impaired people appear at the bottom corners of television screen. According to the teachers here, however, CWD and even teachers of hearing impaired children could only understand part of the notations because the notation/sign language system in Viet Nam has not been standardized yet: “Many notations are very difficult to understand because the notation system is used in Ho Chi Minh City in a different way compared to that in Bien Hoa, and even 14 year-old girl in Khanh Hoa this school). Few hearing impaired children in the two provinces can access the two above-mentioned T.V channels. In reality, the study team has never met any hearing impaired child who has ever watched either one of the two channels.

Communication quality

Communication quality at the community level is limited due to the lack of communication skills and post-communication supportive mechanism. The information sharing mechanism in the community through official personnel and loudspeakers is mainly one-sided, meaning one person speaks or reads to an audience without interaction or illustrative images or evidence to facilitate audience's retention of information. This one-way communication plus people's passive information-seeking habits sometimes leads to "information waste" or inadequate information. Both of the study districts had examples of households who did not ask for their rights and interests and missed opportunities although they were aware of their potential to be beneficiaries of social welfares. For instance, the Red Cross society in Gia Canh commune, Dong Nai, occasionally gives gifts of charity. Many people do not know about the event so they do not go to receive the gifts although they are entitled to. Binh Thuy commune, An Giang province also experienced poor households who did not receive school exemption and reduction for their CWD due to expired poverty certificates. They hesitated to apply for an extension of the certificate or did not even know how to prepare the application, like the case of a mother with a 14 year-old, visual impaired son. She lost the opportunity to get reduction in her son's school fee. Consequently, the mom decided to let him drop school at the beginning of 7th grade school year. Many other families with severe CWD have heard about social protection centers and exclusive schools for CWD through such channels of communications, however, they are vague about opportunities and difficulties when their children go there. In the end they decide to keep their children at home and take care of the children on their own:

> *We have heard about women (in the hamlet) saying that there are schools for CWD at the provincial level but I am not sure what will happen to my kids when going there.*
> *I am concerned if they will be attentively cared for like at home or not so I did not send them there*
> (FG with parents of disabled kids in Binh Chanh, An Giang, who do not go to school)

The backward communication system, both in terms of form and quality, largely contributed to the poor information on CWD's rights in two study districts. Even a high school cadre (cadre of archives) in An Chay town, Chau Thanh, An Giang with a child suffering from cerebral palsy for over the past 12 years, did not understand the nature of inclusive education and her child's right to an inclusive education. Therefore, the mother only considered sending her child to a primary school. Now the child is 12 years old. At the FG with schooling CWD in Binh Thuy, a mother with a child suffering from Down syndrome said that she had not known where to ask about her child's situation. She had to keep her child with her for 11 years, feeling restless that her child would get some interest one day (According to a mother in Vinh Phuc hamlet formerly known as Vinh Tuyen, in Chau Phu district, An Giang). Another example involves a 9 year-old child who has the habits of a dog. She lives with her father who can not support the her. Although she is able to learn, her family knows nothing about her rights.

Additionally, those parents who take the initiative to ask for information from health care and education facilities are often not satisfied with whatever they gain due to the lack of information and consulting skills at the facilities. For instance, a mother with a 12 year-old girl suffering from cerebral palsy in An Chay, Chau Thanh, An Giang, went to ask for information on her daughter's study, but had to return home disappointed. Only when her daughter reached the age of 12 did she get sincere and detailed advice on the child's study (during a visit to her home of the study team and the provincial cadre in charge). She did however get full and useful advice from a rehabilitation doctor at Long Xuyen general hospital, though. She is among few parents in the study areas who accessed such a good source of information on health care and rehabilitation.

Although communications quality remains limited for parents, the very diversification of communication channels facilitates CWD with important values for life. This pattern is dominant in the groups of children who are learning or who have been to school. Among the values, the rights of equal treatment, self-respect, and life endeavors are the values that they apprehend the most. They have learnt such values from lessons at inclusive classes; through the teachers' behavior toward other classmates in the way that "anyone who bullies those with disabilities will be punished"; and particularly through means of mass media and community events to recognize CWD who overcome difficulties and learn successfully and are even brilliant at work. Following are typical quotations for several CWD who are aware that "CWD can do miracles":

> *There is one boy with disabilities who is very good at learning in my commune. He is armless but still can ride a bicycle. He even carries a non-disabled friend to school by bicycle.*
>
> (FG with CWD ranging from 15 to 18 years in Gia Canh, Dong Nai)
>
> *The commune sometimes organizes to offer gifts and bonuses to CWD that overcome difficulties. Many people come over and so do CWD. Hence, they are given with more motivations to strive*
>
> (Inclusive elementary teachers in Phu Vinh commune, Dong Nai)
>
> *We watch T.V, read newspapers and know about examples of talented disabled people. Some of them become an owner of a computer company. I admire them a lot. I got very sad in the past if somebody talked about my disabilities. I did not have any one to share with. Since knowing about such examples, I am not sad any longer*
>
> (One 17 year-old girl with defects in her legs and arms,
> in Khanh Hoa commune, An Giang).

5.6. Public and Entertainment Services

Entertainment activities

Most of CWD take part, spontaneously without adults' instructions and protection, in many folk games with a lot of exercises whether they are, at home, in the community or at school. They often play with one another, usually with able bodied children in games such as cats catching mice, shuttle cock, soccer, dragging, skipping, blind-man's-buffs, hide-and-seek, marbles….

Nevertheless, those children with severe mobility disabilities (like crippled legs) or behavioral disorders (epilepsy or mobility disorder) rarely have the chance to join in the above activities. In their minds, they all want to play very much, and even when they can not play, they feel glad to be with their friends. For instance, Truong, a 4th grade pupil in Phu Vinh, Dong Nai, got a crippled leg after an accident so he can watch other kids playing but can not join in.. Although he can not play, according to his teacher, he is still very glad: "I am very glad when watching my friends playing games" he says.

Most of CWD play equally with able bodied children in such games. They get encouragement and help from non-disabled peers to play whole-heartedly even when they are less able than non-disabled kids:

> *There are kids that chip can not run fast, however, they still join in a running race with the non-disabled kids in the hamlet. They are divided into two teams and run together. Concerned about his pains so he can not run, one healthiest boy in the group carries him on his back and runs very fast so that members of the other side can not catch up with them*
>
> (According to the mother with non-disabled kids in Gia Canh commune, Dong Nai).

It was rare to hear of CWD being denied the chance to play games with non-disabled children right at the beginning. In any such cases the children normally suffered from intellectual impairment so they did not understand the games' rules or had behavioral disorders that caused obstacles during playing of the games. For instance, one 17 year-old child in Phu Vinh commune, suffering from intellectual impairment, still goes to school but his friends never play with him. He has to sit alone in the classroom during breaks. Another story involves a 10 year-old child who can comfortably walk, but occasionally keeps rushing into pedestrians to hold their hands. He likes playing with marbles a lot but other children did not like to play with him because his "strange behavior". His family has to buy marbles for him to play alone or with his younger brother.

There are some exceptional cases where minor disabilities that do not affect the child's mobility, but the children are still bullied by their friends so they get a complex. They are not interested in any games. For instance, one 17 year-old girl in Khanh Hoa, An Giang with a defect in her left hand due to a burn from boiling water, refuses all chances of joining in with friends such games just because she gets a complex about her wrinkled-looking arm: *"I have never played with my friends as I am concerned about their disparagement. Some of them sometimes bully that I have ugly skin, I get sad so I do not want to play with them".*

Besides traditional games, local communities or inclusive schools did not have other amusement, recreational, physical training activities appropriate for the children disabilities types, especially with the group with severe disabilities and intellectual impairment. Local authorities occasionally give gifts to CWD during holidays (Mid-autumn festival, Tet) but they do not organize any community activities which CWD can join in with along with non-disabled children. An exceptional case is associated with Gia Canh commune. It organizes summer activities for both non-disabled children and CWD at the hamlet cultural house, but the activities such as these are not common for other communes. Inclusive schools, as a neutral environment for both CWD and non-disabled children, lack games or equipment for children with severe mobility disabilities. Physical Education has similar failings with children with severe mobility disabilities sitting and watching their friends running, jumping, enjoying themselves during exercise lessons or extracurricular activities. There are not any games that are relevant for intellectually impaired children in the inclusive environment either.

Exclusive schools show success in creating appropriate playing environments for different types of disabilities, but do not create enough inclusive opportunities for the children in the outside world Games at exclusive schools are varied and suitable for different disabilities types. Nevertheless non-disabled children are absent from those games so this does not actually create opportunities for CWD to learn about non-disabled children and vice versa. Outside main school hours, they are taught music, household arts, and painting. Many children are passionate about those subjects and consider them as recreational. In addition the schools also organize events with the wider community by inviting individuals, organizations and children from common schools to those sessions or fairs with product displays or gift-offering events in charity activities for CWD. Unfortunately, most of these events take place at schools, not in the community. This inadvertently isolates CWD in their limited world and makes the outside society look from a distance regard them as strange children:

> *Once we took them to a wedding party of a male teacher. Hearing impaired kids joined us, too. During the party, they talked with one another by using "notation language". The whole team talked in such a way. Wedding participants found it strange so they stopped, staring, showing they did not understand anything at all"*
>
> (According to a teacher at Bien Hoa nurturing center)

Recreational activities at social protection centers remain very poor, except at the Bien Hoa nurturing center for CWD and orphans. The key reason lies in the fact that such facilities focus on nurturing and caring for CWD, but do not have sufficient facilities for spiritual care or recreation. Apart from some ferris wheels and colored balls or similar objects for the children to play with, there is nothing else for them. Bien Hoa nurturing Center is exceptional in preparing and organizing amusement, recreational activities, and catering for their spiritual development. The precinct and classrooms are decorated in a "friendly learning environment" style with the children's' creations (like knitted rattan, bamboo, picture etc). In addition to games relevant for different disabilities types and the children's' abilities (skipping, soccer, ferris wheel etc), the kids are taught to draw pictures, music and rehabilitation. Besides, the center occasionally organizes outdoor activities and summer vacation for the children (bathing in the sea, dancing and singing)… However, there remains a lack of opportunities for their real integration with the outside community (similar to exclusive schools).

Besides games and exchange sessions, CWD often watch television (particularly films and game shows), read newspapers, listen to radio or do things that they like on their own such as drawing pictures, collage etc. This pattern is similar in all types of disabilities and in all contexts. For those children who can not play games due to their severe disabilities or due to having a complex, or being rejection by their friends, such activities are regarded as the most suitable recreation. For instance, one 14 year-old kid in Gia Canh commune, Dong Nai dropped out of school while she was in 2nd grade due to her epilepsy. Concerned about her safety, her family mainly keeps her at home and rarely lets her go to neighbors alone. She draws pictures for her recreation. She draws whatever she likes and whatever is relevant to her. She draws what seeing or from her imagination. She asks her mother to buy painting brushes and papers. Her mother buys her all her necessary supplies so she draws every day. A child (16 years old in Gia Canh commune) who suffers from such a severe intellectual impairment that he can not remember his name and can not look after himself. But he likes listening to songs on radio or television. Although he can not speak, he can pronounce based on music and whenever he wants to listen to songs, he will come over and tap his hands on the television or radio.

Public services

Architectural works, transport system, parks, public toilets, and amusement parks in the two provinces barely incorporate disabled people's needs. In An Giang, there is only one recently built park that partially meet the needs of the disabled. The park is located in Long Xuyen center. According to an expert of the social protection center, this is the first work of the province that is officially tailored to people of disabilities. Its toilet area has paths designed for disabled people. This design model also appears in An Giang's school for CWD – also located in Long Xuyen center. The school's corridors are paved with coarse tiles in the middle so that visually impaired children can trace the way. There are free bus services in Dong Nai for CWD who attend Bien Hoa exclusive school. However, they must have bus commutation tickets registered by the school. It is hard for CWD in the community and at inclusive schools to access this service. Besides above examples, the study team has never heard about or observed any work designed specifically for disabled people.

5.7. Vocational training and employment

Vocational training and guidance network, and employment opportunities

Vocational training and guidance for CWD in both provinces encounter many difficulties through recruitment, training process and creating employment opportunities for the CWD. In Dong Nai, all 9 districts, 1 town, and 1 city has a vocational training and employment recommendation center, but only four of those centers has a function of vocational training for CWD. These are in Dinh Quan, Trang Bom, and Long Thanh-Nhon Trach districts, and the provincial vocational training center in Bien Hoa. No single vocational training center for CWD is available in An Giang where vocational training for CWD is provided through the provincial school for CWD. This school accepts the expected number of CWD from communes and allies with vocational training centers (upon case contracts). Main vocation training subjects include tailoring, knitting, household arts (paper flower folding, nail trimming, and hair cutting), carpentry, and domestic electronics appliances. However, vocational training for CWD is not easy as it requires teachers specialized in teaching CWD. Almost all vocational training centers have not been able to meet this requirement yet.

Creating job opportunities for children after the training meets with various challenges and uncertainties which are largely due to the variety of the recruiters' demands and CWD's abilities. Vocational training centers, Labor and Social Welfare Service, and vocational training organizations, have taken initiatives or collaborated with families with CWD, to build up links and sign contracts for recruiting CWD after training with enterprises in the province. But they failed to work out sustainable measures due to such factors as: supply and demand of jobs and labour; CWD's educational levels and health conditions; technical requirements; and distances from their homes to working places.

Firstly, the search for employment opportunities for CWD is subject to time/moment variation. At times, an enterprise needs to recruit employees; however, CWD may not qualified enough. But other times, after CWD have been trained, opportunities can disappear. Secondly, CWD's educational levels commonly do not meet recruiters' requirements. Normally, enterprises expect to recruit people with good educational levels. According to senior executives at Dong Nai social protection center, some factories demanded CWD to have at least finished high school, then reduced their expectation to secondary school graduation, and later even to literate CWD at the lowest level (when they failed to get enough CWD employees of the higher educational achievements). Still, not every CWD can meet that norm. CWD's health conditions also make many recruiters cautious:

> *Over the past time, some enterprises have come to the locality, requiring the locality to recommend people to work for them but they will not recruit disabled people. They will only recruit those people in good health conditions because they are concerned that disabled employees will affect working results. They operate for profits, thus the requirement is rational.*
>
> (Gia Canh commune's women association, Dong Nai)

Thirdly, most technical processes, machinery standards and production supportive equipment at enterprises were not originally designed for CWD, and thus not really suitable for them. Therefore, enterprises will have to adjust those tools (like chairs and tables) if they want to recruit CWD. Fourthly, enterprises are located too far away from CWD's houses, making them hesitant when deciding whether to work there. This is common in the two study districts where the majority of the residents work in agriculture and where none of the production facilities operate. For example, there is one vocational training center for CWD in Dinh Quan district, Dong Nai. They learn how to knit and make clothing there. The center has been operating for 2 years so far. The garment factory, however, is located 70-80 km away from the center. As for knitting, the children do not have to go far as they could bring raw materials for knitting products home. But it is the instability of the market (selling their products) that discouraged them to pursue the job. According to personnel in charge of CWD in Dinh Quan district: *"If stable jobs or employment opportunities are available for them, it will be very easy to encourage them to take vocational training. Now they are not assured with instant jobs to do in the locality so most of CWD here stay at home and help their families".*

The two provinces, however, have documented some successful cases of vocational training and employment creation for CWD. Dong Nai province possesses two examples of this type. One of them is the Long Thanh garment enterprise which receives almost 100 CWD (of working age) who are provided with accommodation. This enterprise also redesigns machines and assigns tasks relevant to the enterprise's demands and tailored to different disabilities types. This model has been operating for 2 years in Dong Nai. The enterprise owner also operates a social protection center for CWD in Long Thanh. According to the plan, the disabled children in that center will be given vocational training and chances to work at the above-mentioned garment enterprise. The other model is an association of disabled people who overcome difficulties to better themselves in Xuan Loc district. It was set up and is managed by a person with disabled legs. This association specializes in repairing home appliances and electronic equipment. Repair fees go towards maintaining the association's operation, to supporting the members and to offering vocational training for other members. The total number of members comes up to 20. In An Giang, there is an allied model between the provincial school for CWD and Kim Chi garment enterprise in Long Xuyen city. However, this is an individual relations-based alliance, but not systematic or long-term.

Barriers and motivations from families' side

Poverty, parents' feeling sorry for CWD, and CWD's health conditions are barriers to their vocational training

The cost for vocational training is a big barrier for CWD and their families. Although CWD are supported with free vocational training and allowances for the first three months in line with social welfare policies, related costs like traveling expenses and accommodation, and distances between the children's vocational training places and their houses often worry the children and their parents. Many parents are very poor (living on the breadline) and are unable to afford such expenses. At times, the children's' travel costs are considered as losing opportunities for their families to earn money although it is free of charge:

> *The kids often have to stay away from home. If they go to learn, a working day is lost. The province supports learning expenses, but parents hesitate to let their kids study there as their home economics remain poor.*
>
> (The person in charge of children protection in Binh Chanh commune,
> Chau Phu district, An Giang)

Besides poverty, feeling sorry for the children was a consistent concern of parents who were worried about their children's hardship during the training process. It also discourages parents to send their children for vocational training. That is a common statement in the two study districts. Most of the parents with CWD think their kids are disadvantaged "not as good as their friends", thus they are given more than other kids in their families. They are often cared for by their parents and family members when at home. But while at the vocational training place, they would have to take care of themselves in addition to other potential challenges that they have never experienced due to the lack of socialization: *"Most of CWD over 15 years old are used to housework. They have never been away from home nor have they had living experience"* (According to personnel in charge of children protection in Dinh Quan district, Dong Nai).

Obviously many kids with severe disabilities can not take vocational training. This situation is also very common in the two study districts. The children in this group are those with intellectual impairment, behavioral disorders or serious conditions like epilepsy.

Without worries about poverty and CWD's health conditions, families serve as an effective motivator for vocational training and success of their CWD in job markets

Some families support vocational training for CWD and take initiatives to provide vocational guidance or motivate them to attend the training. Regrettably, the number of those families remains small and is often the wealthy parents who are either officials or far-sighted about their families' future. For instance, some CWD in Gia Canh commune followed their parents' advice and undertook vocational training, they later successfully applied for a job. The following statement illustrates the confidence of the head of Gia Canh commune health station about these cases:

There are two disabled people in the locality. One learnt clothes-tailoring and the other learnt about domestic electronics appliances. They now had their own stores of tailoring and electronic products' repair. Both of them make efforts to attend vocational training so that they can earn their own living. They often get pieces of advice from their parents "We are not still young and can take care of you. We will not be able to care for you when getting older. You must try to learn to have a career to care for yourself… Both cases fall into wealthy households and the kids suffer from slight disabilities so they can work by themselves.

5.8. Values and life skills

Opinion on friendship

Friendship is spiritually important for CWD both at school and at home. Most of CWD in this study (except for those with severe disabilities or complexes) value friendship and feel happy to have friendship. Thanks to their friends, they are not discriminated and get the chance to join in games with non-disabled children… Non-disabled children commonly carry handbags, lend pens, and particularly protect CWD against. More importantly, when they are sad CWD tend to seek comfort from their close friends, rather than from their parents or teachers.

Each time I get sad because of my mom's scolds, I go to the field alone or meet my neighboring friends. I will get less sad when playing with them. I have 4 close classmates since the time I learnt at 1st grade until 5th grade. I talk and play games with them when getting sad. Now, I do not have anybody to confide with or play games with as they dropped schools when learning at 5th grade.

(The girl in Binh Thuy commune, An Giang, with a defect in her lips, is learning at 8th grade)

When they are not welcomed or allowed to play with their friends, CWD often isolate themselves within their own world, becoming lonely or looking at other children playing with a desire to be friends. Such cases often occur at inclusive classes rather than in the community. For instance, one kid with intellectual impairment, in the 4th grade at Phu Vinh primary school, in Dong Nai has never been accepted by his classmates, so he often stays inside the classroom on his own during breaks. Another child, who is also in the 4th grade at this school and suffers from a defect in his arms, is not allowed by his friends to join in the shuttle cock game just because he plays shuttle cock worse than his friends:

I play shuttle cock worse than my classmates but I want to play it a lot. Friends at school do not allow me to play so I get sad whereas neighboring friends play with me in a pleasant way so I prefer to play with my neighboring friends.

Opinion on family

For most of CWD, the family is a loving environment and a place they find more comfortable and safer than any other place. This is clearly shown through their pictures at FGs (including the learning and non-learning groups under 15 years old). When asked to draw whatever they liked, most of them drew pictures of houses, explaining that home is the place that protects them and that they find more comfortable than any other place. Following quotations prove this:

> *I can do whatever I want to at home whereas at school, I can not*
> (One child in Binh Thuy commune, An Giang shared).
>
> *Home is the place where I return wherever I go. Home is the safest place. All family members love me*
> (One 15 year-old girl in Gia Canh commune, Dong Nai)
>
> *All family members understand me so they do not bully at me while many outsiders bully me, making me sad*
> (One 17 year-old child in Khanh Hoa, An Giang).

In their mind, the CWD's family is embraces the close relations they have with neighbors, with close friends nearby, even with pets that they are fond of, but not simply restricted to their parents or siblings. Many of them also said that they had more close friends in their residential areas and could play with them comfortably. Moreover, the friendships with their neighbors is often close. They find it easier for them to share with neighboring friends than with those at school. So the intimate friendship with neighboring friends subconsciously links CWD's happiness with their homes: *"I love my home as many neighboring friends come to my house. I can hang out to the satiety with them"* (One 14 year-old boy in Binh Thuy commune, An Giang).

A typical house painted by CWD in both provinces

The family image in the eyes of severely disabled children who can not draw much nor communicate is highly typical. This group can not even draw a picture of a house, but some of them can draw pictures of animals they love such as dogs, chickens, and cats. Usually, this group is not taught how to draw but they manage creating shapes of such animals. When asked to talk about their drawings, they can only answer curtly "chicken", "dog", or "cat". They may be the dearest images that they see every day in their houses.

CWD also draw animals around them (for example ants – An Giang)

Regrettably, among those CWD that go to school, only one child did not draw a house but mountains and nature. That is a girl with a cleft palate. Now she is in the 8th grade. The picture shows a girl who is standing alone, some boats floating along the river and some mighty mountains.

She told *"I love nature as I feel more comfortable in nature than at home."* When probing further, the study team found out that she was often scolded by her mother as "obstinate stuff" or 'pesky stuff', even beaten every time she broke bowls or plates or refused to go to market with her when told so. This is the only child who drew the nature instead of a house.

For CWD, the love and care of relatives, especially parents and siblings, play vital roles in nurturing their spiritual health. They inherently have inferiority complexes due to their disabilities so they often have needs to enjoy and communicate with their relatives. They often feel empty and even hold their relatives responsible for their absence from home or not spending time playing with them. This is particularly true with severely intellectually impaired children because they do not have anybody else to play with them (not even their neighbors), other than their relatives.

For example, a 14 year-old child with intellectual impairment in Phu Binh commune, Dong Nai, reproached his siblings when asked "what at home makes you sad?". He explained that "as my elder brother and sister go to pick blackberries and do not stay at home to play with me". However, he did not reproach his parents although they also go to work, simply because they work less and still spend time "having fun" with him. Such examples suggest how much CWD need their family's love and emotional support.

Opinion on school

CWD in this study do not have any special impressions of their schools, other than the friendship at school and team games. Their greatest joy is to play games with non-disabled children. Both children who directly join in games and those who can not join in due to their severe disabilities said the same thing: *"Although I can not play, I am glad when sitting, watching my classmates playing"* (One child with a defect in his right leg so he must sit in a wheelchair at Phu Vinh primary school, Dong Nai). For those who can play with their close friends, such joy is multiplied because they not only have chance to play games, but also get support and protection from their close friends.

Noticeably, while many pupils at inclusive schools admit that the teachers treat them well but they do not show them love. Results from many FGDs with children and inclusive teachers show that CWD get the chance to listen to the teachers' stories, to learn how to draw, to sing, the Vietnamese language, to do math etc in the classroom and even receive attentive teaching during breaks or private lessons, however, the majority of learning CWD do not express a liking for the teacher. This lack of liking teachers is because of the fact that teachers still gave out more punishments than rewards when dealing with their pupils. Results from FGDs with CWD at primary and secondary schools in both districts showed that the use of punishments (both for non-disabled children and CWD) remain common while there is no relevant way to encourage them at inclusive schools. For instance, when a CWD gives the right answers to a question from the teacher, they will receive the reply "correct" but will not be praised.

On the contrary, anytime they give the wrong answer, the teachers are angry: scolding them, glowering at them, beating them on their hands or hips with a ruler, even pulling their ears. The children also acknowledged that the teachers do so habitually for both non-disabled children and CWD, but not only for CWD. Actually, CWD inherently possess complexes that are more likely to get bigger each day due to such unfriendly behaviors from the teachers. In many cases, such behavior from teachers widened the gap between them and CWD:

> *I dare not tell the female teachers when I feel sad. I dare not tell her about any difficulty. I get afraid when looking at her as usual. I would get more scared if asking her. Who darets?*
>
> (One boy with disabilities in the arm in Khanh Hoa commune,
> An Giang who is learning at 9th grade).

Out of all FGDs and in-depth interviews, the study team met only one 17 year-old child in Khanh Hoa commune, An Giang (with a defect in her arms) who like the female teacher. The reason is so simple *"I find her close and love me so I share with her when meeting difficulties or having any sadness. After telling her, I feel very comfortable"*. Perhaps, teachers' attention, friendliness, and empathy play a role as catalysts to pull CWD closer to the teachers.

Opinions on neighbors

Relations with neighbors are crucial as they form a stable playground and a pathway to connect CWD with the community, especially when their neighbors have children of the same age as CWD. The CWD was born and grew up with them. Out of school hours, CWD mainly communicates with them. Most of CWD in this study are delighted when their neighbors visit them or when they go to the neighbors' for fun. And in those relations, "the neighbors' children" play decisive roles to connect CWD with the adult neighbors. This is easy to understand because when children are close with one another, their parents will feel sympathetic toward CWD. At times, as children play with one another, neighbors care for one another more. Such interaction among the neighbors makes children feel they are sympathized with, understood and protected:

> *Neighbors are those who understand me so they do not bully me. They are close to me. They even avoid talking about my disabilities when going to my house. As for other people [strangers, not neighbors], when seeing me walking lame, they imitated or talked hard-to-accept words, which made me sad.*
>
> (One 16 year-old child with a defect in his left leg, in Khanh Hoa commune, An Giang)

However, CWD in urban areas do not always live in such a friendly neighborhood because "neighbors" are often away from home for work. Without such relationships, the children try to establish and preserve solid relationships with their relatives. Sometimes, it is not always easy for CWD to do so:

> *My parents and siblings are absent from home. They just come back home in the evenings. I wish neighbors to come to my house, but they are busy at work. So are my parents. I visit my maternal grandma who lives 1 kilometer away*
>
> (The confidence of a 10 year-old child with eye defect
> in Phu Vinh commune, Dong Nai).

CWD’s life skills

In general, CWD’s lack communication skills, especially when showing their emotions to others. They commonly hold back their feelings about troubles and unfairness shown to them by other people. This pattern is common in both study districts, with both children who go to school and children in the community. For instance, one child with intellectual impairment, learning at 4th grade at Phu Vinh school in Dong Nai explained how one boy bullied him, hit him, rummaged through his school bag and broke the window near his seat (it was very hard to hear this boy so the study team needed the person in charge to interpret the conversation). Regrettably, he did not tell his teachers and classmates about that bullying. Another girl, learning at 2nd grade, also at Phu Vinh primary school, has a defect in her left eye. One classmate occasionally (the one sitting at a table at the back of her class) bullied her saying “the blind stuff”, “the squint stuff”. She got sad but did not cry. She wanted to tell her parents about her sadness, but thought it would upset them, so she had constrained herself for over the past two years. It was only when she related the story to the study team that she burst into tears in front of the school’s pupils during the focus group on that day.

CWD in An Giang also held back their feelings in the same way. For instance, a girl learning at 8th grade had a defect in her left leg so she could not walk properly. Some pupils at the school bullied her as “the crippled stuff”. She became very sad but was determined not to tell her parents who cared for her a great deal, just because “she does not want to make her family miserable”.

While most of CWD tend to hold back emotion, some of them developed delicate yet effective skills (social-networking skill) in dealing with people around them, which not only helped them avoid sneers and bullies but also strengthened their existing relations. For instance, a 12 year-old girl with cerebral palsy who has to walk with crutches (in An Chay town, Chau Thanh, An Giang –case study III), had always been bullied by a neighboring boy, some years older than her. He imitated her way of walking with crutches. She got annoyed with him, but never for long and even responded to him with very friendly actions: *“He bullies me, imitates my walking way. I get sulky with him but not for long. I even give him with candies. I have 3 packs of candies, I give him two, and I take only one.” When the study team asked “why don’t you remain annoyed with him for long but even give gifts to him?”* She happily answered *“I would not be a good kid if not doing so. I watched television programs telling about such good kids”.* It is worthy to note that this girl is well cared for and receives endless loves from her parents, grandma, and neighbors. Perhaps these values are reflected in her own good behaviour.

Another girl with the left arm burnt by boiling water has a nice but different way of communication. When feeling uneasy because she could not carry out a chore with her friends, she took the initiative and shared her concerns with her classmates: *“I am so sorry for not being able to arrange desks and chairs with you. If there is any other work, let me do with you.”* After that, the whole team on duty was happy: *“They smiled and I was happy, too”* (she said smiling).

Motivations for CWD to overcome difficulties

Images or stories about disabled people in real life, on T.V or in newspapers, magazines, books, even on Internet are interesting topics for CWD and often give them more strength to get through life’s endeavors and challenges. Many children admitted that such stories helped them to have more objective and sympathetic thoughts for disabled people. Some even uttered: “Through such stories, I know other people suffer from more severe disabilities than mine and live a harder life than mine, but they managed to overcome them”. More importantly, examples of disabled people who overcome difficulties and become successful in life, often give strength and motivate them to continue striving and reduce their inferiority complex: *“I strive more to realize my dreams when knowing about examples of successful disabled people”* (The 14 year-old child with the defect of sticking hand fingers, already operated). The 13 year-old girl with a tender face and smiles, but with paralyzed left arm in Khanh Hoa, An Giang, often has inferiority complex with emotionless looks and words, finds her strength from such stories: *“I no longer feel inferior when seeing them so. It is easier for me to ignore whatever they say”.*

CWD’s aspirations

The two major dreams and aspirations of CWD are to continue learning and get a relevant job and to wish for their disease not to get worse. CWD in An Giang are often more open-minded than those in Dong Nai and often hope to get a job rather than wish their diseases not to get more severe. For instance, all CWD at the focus group with 10-15 year-old CWD that are learning in Binh Thuy commune, Chau Phu, An Giang, were open-minded to share their aspirations without any hesitation. One child learning at 2nd grade (with severe shortsightedness in both eyes) dreams of becoming a doctor; another one, learning at 3rd grade (with a paralyzed left arm) dreams of becoming an accountant; another child in the 8th grade (with cleft palate) and other children in the group dream of becoming teachers. There are few CWD, however, who wish to be like non-disabled children (this child has an extra finger on his left hand and often suffers from dizziness). I wish to get healthy so I can help my family.

Most of CWD in Dong Nai, even the learning group, are very reserved about express their aspirations and often wish their diseases not to get more severe rather than dreaming of a job or career. Some of them in the 15-18 year-old group slowly talked about their aspirations after a range of probing questions and encouragement from the researcher while the 10-15 year-old group that was joining in inclusive education did not say anything at all. Most CWD in Dong Nai had aspirations that were related to diseases and health (like their wishes to recover from the diseases; or not to be affected in the other eye), but were not generally related to learning or vocational training in the future. Three out of all CWD joining in the study in Dong Nai dreamed about careers. Two of them suffered from cleft palates, which had been operated on, and the other had a defect in her legs so she can not walk fast. All of them live in Gia Canh, Dinh Quan. One girl (cleft palate), learning at 9th grade, wished to become a doctor to treat her own disease and her relatives. One boy (cleft palate), learning at 10th grade, dreamed of pursuing a career in electronic-products. Another child with defect in her legs dreamed of becoming a tailor.

5.9. Family and Social attitudes and roles

Attitude of family in caring for CWD

At home, regardless of the disabilities the child has and although CWD are normally considered as the family’s burden, the parents’ affection and humanity cause parents to give more love and care for their CWD. Most of CWD are looked after by affectionate parents.

In general, parents tend to accept their own CWD as a more disadvantaged member of the family and therefore often gave these children more affection and care compared with other children in the family. For the slightly disabled children, those priorities just stopped at verbal pampering such as “say sweet things to these children”, “not using strong words or telling off” as the way they often treat non-disabled children. For children with more severe disabilities which affected their daily activities, parents often spent more time taking care of them:

> *Normally my son cannot eat hard food and just eat soft stuff like rice soup or milk. Sometimes when I cook rice soup with meat for him, I often leave the meat out because I am afraid that he will get choked. Even when he goes to school I do not let him eat everything, just milk or soft cake. When he goes home at noon, we have lunch together.*
>
> (Mother of a CWD learning at primary school in Gia Canh commune, Dong Nai).

For children with severe disabilities, especially with intellectually impaired and behavioral disorders, that affection goes hand-in-hand with continuous caring effort and even with a chronic psychological burden due to medical and psychological changes which the child has suffered from or brought to their family. Many people do not dare to let their child play for a long time outside their house or stay at the neighbor’s, fearing that their child will be a bother to their neighbor. These parents just buy toys for their CWD to play at home or play with his siblings:

> *My son knows little. Meeting alien people, he just comes to shake their knee. He cannot speak so he does this to ask their name. When he comes to any family, they often give him anything eatable and ask him to bring home. It's just a way of asking him to leave because they do not really want him to play at their house. If he stays there, he will make fuss of everything so I have to buy toys for him to play at home with his siblings.*
>
> (A mother having an intellectually impaired and behaviorally disordered son at Gia Canh commune, Dong Nai)

There are mothers who strive to overcome their pains and disappointment to care for their CWD without any ability. For example, a mother at Gia Canh commune, Dong Nai is always beside her 16 year old son who cannot himself do anything for himself: he cannot eat and he can not keep still either (he is intellectually impaired and behaviorally disordered). Usually she would have gone out to work however because of him she just stays at home and lets her husband earn the living. Everyday, she just has one duty i.e. looking after her son, cooking and giving medicine to him. She loves her son very much and always hopes that this will make progress so that one day, he can take care of himself and can pronounce just some words. She decided to save money and took him to a center for the disabled in Bien Hoa city (she cannot remember the name of this center). Each month, she had to pay the fee of 600,000 VND (around 30 USD). That was 10 years ago. This sum of money is not small but she thought that she was doing a good thing for her son. She left her son at this center but she still visited him every week. But noticing he became weaker and weaker, thinner and thinner, she and her family brought him home after several weeks or "he would die". After that she decided to live with him until now. This mother also emphasized that *"at home, I give him many meals a day. He cannot eat food that was cooked in that center. Just me, his mother can understand and have time to care for him".*

Another mother from Khanh Hoa commune, An Giang has a 14 year old girl who is so severely intellectual impaired that she cannot take care of herself, cannot speak and just stays in one place all day long. The most, she can do is move for some meters but this daughter receives very good care. The research team visited her and witnessed a tidy and nice room which her mother prepared for her. And she herself looked very clean. Although she cannot move a lot, there is absolutely no smell in the house. Both her parents are busy with work but they still spend time taking such good care of her.

However, in poor families and with few members, CWD usually receive less care no matter affection their parents give them. And this kind of situation is common in the two researched districts. Normally in these families, both the father and the mother have to go to work and the caring for their CWD follows a very simple rule: "the older child takes care of the younger one while parents have to earn money for their living". Sometimes those families have to leave their CWD alone at home or send him to anyone who was at home, even to a blind old woman at the absence of other children:

> *My family is so poor that everyday we have to do anything others ask us to do. We love our CWD so much but we have to accept because we have to raise other kids. My husband and I work from morning till night and we leave our kids to my blind mother. We know that it would be dangerous but we have no choice.*
>
> (Parents with CWD preparing to go to school at Binh Chanh commune, An Giang province)

In summary, parents always are the source of sympathy and encouragement for CWD. Although they have difficult situations (are poor, busy or lacking people to care for CWD), most of their CWD receive the priority of care from their parents compared with other children in the family: "my parents usually give me more priority than my two older sisters. When eating, they often give me the best food. Just so but I feel very happy" (a 17 year old girl who has a burned arm, Binh Chanh, Chau Phu). For some CWD, their parents, even if they do not give them preferential treatment in the family, they do not discriminate against them and always make them feel secure. Sometimes the parents become sources of sympathy when they feel inferior because of discrimination from other people:

> *“Sometimes there are people discriminating against me and that makes me so sad. I went home and talked with my parents and they said that ‘you still have parents which is luckier than many others who do not have parents’. And I feel very happy”.*
>
> (A 17 year old girl with burned arm, Binh Chanh, Chau Phu, An Giang)

However, some CWD don’t receive care and understanding from their parents, so they feel very lost and look for a solution from outside the home. For example, a CWD in Binh Thuy commune, An Giang was told off by her mother and even beaten whenever she broke things. The gap between her and her mother is getting bigger and bigger to the extent that she couldn’t tell her mother anything. When sad, she has to go to the field or play with her neighbor’s children to forget it. She is the only girl in this research to draw nature instead of her family like the others (for more detail, see the section above on children’s opinion of family). And this is the only case of a CWD who couldn’t find peace at home. Another typical example is a 9 year old girl having habits of an animal in Gia Canh commune, Dong Nai due to the lack of her parents’ care at the first three years of life. (For more detail please see Case Study I). At the moment, she is living with her father and her brother; however she mainly receives care from her parental grandparents, her uncle and aunt.

Besides parents, other people in family also play an important role and they usually give their CWD the affection and care. Among them, the grandmother is the most important one. The research group witnessed many specific examples in which the parental or maternal grandmother plays a very important role. For example for the girl with habits of an animal, her parental grandparents raised her since she was 3 years old. At the moment, although living with her father, she still receives care from them because her father “couldn’t raise himself” so he couldn’t bring up his daughter either.

Another example is the case of a 12 year old disabled girl in An Chay, Chau Thanh, An Giang who is successful in rehabilitation because she was looked after by her maternal grandmother for 10 years (sometimes at Long Xuyen hospital, sometimes at HCM City Orthopedic center). Or a girl at grade 2 in Phu Vinh, Dong Nai has a disabilities at her eye and has no friend to play with. She has to play with her grandmother who lives one km away from her house. And there are many other examples in which the parents have no time to take care for their children and have to rely on grandmother for everything.

The parents and CWD also talked about the role of other family members eg. their uncles, aunts, and siblings, but they just played a minor role in taking care of these CWD. For example, the siblings mainly spend time playing with the CWD and other people can help the parents send them to school, do medical check ups and in some cases helping parents to raise CWD (the typical example is when, instead of her parents, the uncle and the aunt, together with her grandparents, raise a girl with habits of a dog).

Attitude and roles at the inclusive school

Teachers’ attitude and role in the inclusive school

Teachers in the inclusive schools as a whole are interested in teaching and protecting the rights of children with disability (CWD). This appears in all group discussions with inclusive teachers and CWD attending inclusive schools in the two provinces. Almost all teachers at FGDs who have ever taught at inclusive schools say that they take more care of CWD relative to non-disabled children. This includes spending more time instructing the CWD (in breaks, holidays), allowing them to do easier homework and exempting them of hard physical exercise. For instance, in a group discussion with CWD attending inclusive education at Phu Vinh primary school, Dong Nai, the research group asked the CWD to draw tables and chairs in their classes and probed for the interaction between teachers and pupils and among pupils based on the drawing. Findings suggested that almost all CWD were placed in the first rows (1, 2). Only one pupil with the disabled arm (a left hand could not move) was seated in the back row. But the most noticeable thing is that the teachers spend enough time on their pupils to check class work and to give them instruction. The research group also asked

CWD about their learning capacity (listening to and understanding their teachers) and the answer was that they had no difficulties in understanding their teachers. The research team did not identify any sign of stigma and discrimination of teachers against CWD.

In addition, teachers, especially in the inclusive primary school, try to protect the rights of CWD in many ways such as teaching non-disabled students how to behave and support their friends with disabilities, or timely correcting behaviour committed by non-disabled pupils against CWD. For instance, when a CWD was bullied by other students, the teachers often intervene immediately by specific and strict actions such as verbally reproaching, lowering their conduct level, or even beating the misbehaving students:

> *In my class, one classmate is disabled in their leg. He is my close friend. One day he borrowed a pen from a non-disabled classmate but that classmate hit my friend. I told my teacher and she hit him back (the non-disabled one). Since then, he has not dared to bully my close friend.*
> (FG with CWD following inclusive education, Phu Vinh primary school, Dong Nai)

Some teachers, because of their love and responsibility for CWD, taught CWD with all their hearts without expecting to be paid back with incentives or gratitude. There are two typical examples of this spirit. One example is in Phu Vinh primary school, Dong Nai, involving a teacher of grade 4. She sacrificed her time to teach one student with mental retardation during weekends and in breaks. She is the only teacher recorded by the research group, who directly came to students' house to encourage him and give extra-class help. The second teacher coming from Khanh Hoa primary school An Giang also taught in grade 4. She spent all breaks that should be used for a rest, to give extra teaching to a student with mental retardation. Although she did not expect recognition from others, her school and colleagues recognized her as a dedicated teacher and as a good example in the cause of educating CWD.

Heads of inclusive schools also support CWD by bringing a lot of opportunities for CWD to learn, test, and take their exams, and by encouraging them to continue their studying. According to inclusive teachers, previously if one CWD failed to get adequate scores to move to a higher class, he would have to stay down a year. For this reason, many students with mental retardation study and re-study even in "3 or 4 years" but they still could not pass grade 1. This really discouraged the family and the students who often felt no excitement and lacked motivation to study. Fortunately, since the implementation of the inclusive education, CWD have been allowed to attend higher grades regardless of their end-year examination scores. This kills two birds with one stone: bringing happiness to CWD and family and allowing their study to continue. For children with more minor disabilities, the school also has various ways to encourage their studying. For example, Phu Vinh School participated in holding a ceremony of praising disabled children who overcame their difficulties. Some schools in An Giang (Khanh Hoa primary school) delivered gifts to hard working CWD (such as books, notebooks, pens…). Besides, the schools in both districts exempted school fees for disabled children coming from families with particularly difficult situation (poor).

Despite the above-mentioned effort of inclusive school teachers and administrators, they have not yet created a close link between school – family in instructing and looking after CWD. School teachers generally visit student's house only when a CWD quits school, which is often too late because by then the households rarely permit their children to come back to school. The main information channel for families and schools to communicate with each other is parent-teacher conferences at school. But in the study districts, parents often come there to listen mainly but rarely ask for the rights of their CWD or discuss with the teachers about their children's school work and strategies to improve their school performance. The exceptional case is the teacher of grade 4, in Phu Vinh commune, Dong Nai who came to the house of a child with his mental difficulties to talk with his parents about his studying and also gave him extra-class help on week days and weekends. Her kind heart actually inspired this child to study and brought happiness to his family, convincing them that their child was able to learn and to get better in his study and life:

> *From grade 1 to grade 4, he has not talked with any one. Going to class, he only sat. Every one knows that. Since I taught him, he changed remarkably. He, talked and communicated happily. with other ones. He could write and read*
>
> (According to class teacher)

Attitude and role of the non-disabled children

Non-disabled children commonly feel sorry for and support CWD in their studying and living environments. The research group acknowledged a lot of typical examples in which one non-disabled child helps or protects CWD, and these can be grouped into three basic forms of support: 1) Support in studying; 2) Support in games such as carrying CWD on the back when he is tired and accepting him to participate in a game regardless of his playing ability; 3) Support in case of being bullied. During the first form, a non-disabled child can lend a CWD a pen, a notebook, and a book or let him/her copy the lessons or record the lessons for CWD. Many students make use of their breaks to teach CWD the lessons in their class. This peer teaching is also encouraged by teachers of the inclusive classes. Non-disabled students have even carried their CWD friends on their back or taken them by bicycle to school for years. From the second form, the non-disabled children and CWD play together in many games. In those games, the non-disabled students tend to make concessions and accept CWD to play with; even the CWD might not play as well as other ones. In a particular game (running race), a non-disabled student even carry a CWD on their back so that the whole team can be together. (FGs with CWD aged 15-18 and with parents of non-disabled children in Gia Canh commune, Dong Nai). Such supporting spirit prevails in all schools and communities where CWD and non-disabled students play together. Only some CWD are unable to join in at all. They are mainly seriously disabled children (mental retardation or physical disabilities). In the third form, CWD are sometimes bullied by the non-disabled children (razz, backbite and even fight) but they are fully supported by their close friend. Two popular ways non-disabled children use to help CWD are ‘warning the misbehaving ones of their intention to report to or actually report to teachers about the misbehaviors”, or fighting with the misbehaving one to rescue their friend (CWD) (see details of illustration examples in the part of community’s attitude).

Note that those stories of love and assistance narrated above seemed to be more common among pairs or groups of close friends between non-disabled students with CWD. However, such supportive spirit is also prevalent among non-disabled children without any disabled friends. For example, in a FG with non-disabled students in the inclusive school of Khanh Hoa commune, An Giang, most of them had no close disabled friends; some never saw any disabled students in their school and in the community. But all of them expressed a spirit of protecting, helping and supporting CWD with a reason that “they are more underprivileged”: ‘I will record lectures for him, I will carry his bag, and I will lead him by my hand” (one student in grade 3 who never sees a disabled student but states the messages out of his imagination).

Despite the overall willingness of non-disabled children to assist and support CWD, there still exists prejudice and discrimination among a small portion of non-disabled children toward CWD, especially those with mental retardation and visual impairment. However, the phenomenon often disappears quickly and seldom reoccurs with timely intervention by school teachers.

Attitude and role of the community

Affection and emotional support form the main attitudes within the communities in which CWD study and live, and in many cases this attitude is transformed into material support or protective actions for CWD. However, CWD and their families still suffer due to discrimination, apprehension, and unreasonable avoidance from some members in the communities .Of course while assistance and support always bring CWD and their families certain comfort and partially fulfill their material shortages during crisis, it is the discrimination and stigma that cause deep emotional trauma and at times become a spiritual and unforgettable pain.. Unfortunately, such discrimination, stigma, and self-stigma are not seen as an issue in the eyes of the majority of adults: teachers, parents, community leaders and professional officers. They all have the tendency to think that nowadays, society knows much more about disabilities and therefore must be sympathetic and supportive instead of discriminating against CWD. Unfortunately, that statement is, in fact, a dangerous subjective viewpoint which is no excuse for the lack of understanding of the psychological problems of CWD.

Affection and support

Affection and emotional support are the most important attitudes within communities in which CWD study and live. In many cases this attitude is transformed into material support or protective actions for CWD. In schools and nurturing bases, they are given priority in the studying and caring activities. For exclusive schools and social protection centers, it is natural. And for inclusive schools, this is also evident. Specifically, prior to the inclusive program, CWD with insufficient end-year exam scores would have been kept in their current grade. Currently, even they do not get the standard scores; they can be allowed to move to a higher grade. That is policy of education sector based on the commonly-accepted viewpoint among inclusive teachers: "CWD make their progress compared with themselves, not compared with common standards" (Primary school teachers, Phu Vinh commune). Besides, the students are taught Vietnamese and given part-time extra classes with assistance from either the teachers or outstanding students).

In addition, the teachers always express their attitude and actions of protecting CWD through integrating important messages about CWD in civil or morality lectures, or even employing more serious actions such as 'blaming or punishing' those non-disabled children who bully or discriminate against CWD (see details in the part of school's attitude).

Besides, CWD also receive lots of emotional and material support from their classmates, especially from their close friends. There are many stories in the study communes confirming that non-disabled children lend CWD pens, books, and notebooks; assist CWD with study lessons, study together, lead by the hand, carry on their back to school or even when playing games (Phu Vinh, Gia Canh). There are also moving stories in which non-disabled children regardless of danger and risk strive to protect and defend CWD. The following story told by a boy child (Tuan), a non-disabled child, at grade 3 (Phu Vinh commune) expresses that typical support:

Minh, a grade 2 boy, is disabled in his leg (Phu Vinh). One afternoon, Minh came to visit a friend, Hung a his house. At that time, Hung was watching a CD of superman. Minh would like to watch it together. Hung did not agree and became angry and struck Minh. And Tuan (a non-disabled child) and a girl child (Hong) at the same class passed by. Seeing Minh being beaten, Tuan told Hong to continue walking: "Hong continues walking. I have something needed to be done". The words were not completed, Tuan turned back and pushed Hung out and hit into Hung's face repeatedly. The dogfight between two children happened. Finally, Hung ran off. Minh, still painful managed to timely bar his intact leg to make Hung fall down. Tuan held his shirt and admonished "from now you are banned to bully Minh. If not I will set your house on fire". Since then, Hung never dared to bully Minh any more.

*(*Tuan is Minh's best friend).

Although it is a childish and instinctive, and even carrying a childish nature, the story expressed a clearly mutual love and affection of a high spirit of defending weak persons inside Tuan. Anyway, if Tuan had not intervened, Minh would have surely been bullied again in a similar way... However, naturally that behavior also indicated a lack of communication skills and of conflict resolution strategies among the children.

Many stories about mutual love and affection carry female and delicate characteristics. This is a story (told by Mai, a non-disabled child at grade 3, Phu Vinh commune):

> *Hieu, a boy student at grade 3 had mental retardation. On that day, when doing exercise he had no pen and wanted to borrow a pen from a same table classmate named Sang. Sang did not lend him and became angry and then pulled the pen back and hit into Hieu's chest. Witnessing that, Mai intervened and threatened: "Stop, if not I will tell our teacher". Sang immediately stopped. Since then, Sang never bullied Hieu any more.*
>
> (Lan is Hieu's best friend)

Two stories with bullied CWD but the interventions from their peers were totally different. One was acted on the child's own. The other was based on potential adult's support (teacher). The second is much safer and more suitable for children at school.

In the community, neighbors play a very important role in providing emotional and material support to families of CWD, especially for serious CWD in difficult situations. At the study sites, the neighbors are considered as source of comfort and happiness to CWD and their families. Almost CWD in the group discussions in both provinces told that they are often visited by their neighbors. Usually, they barely come to visit but sometimes they come with some small gifts such as banana, orange, some kilograms of rice or some money for medical check-ups. Such visits, whether with or without gifts, make CWD and their families feel very happy. Sometimes CWD take the initiative to visit their neighbors', and they mainly play with their neighbors' children: they play or participate in games. Only children with serious behavioral disorders (throwing rocks, beating others or acting strangely like shaking strangers' knees, or spitting) or children with epilepsy will be kept away from by other people (see details in the part of discrimination).

Discrimination and self-discrimination

Evident or subtle, discrimination exists around CWD and their families in many forms (words, eyesight, evasion, or bullying actions), and sometimes brings stress or long-term psychological injuries to some CWD. Even though the word "disabilities" has become a common term through mass media, people in the two study provinces are still using words like "inborn disease", "dioxin disease", "disabled, cut off", "dumb", "deaf" depending on each type of disabilities. This terminology is still used by some teachers in some disabilities schools – the people who should not use the above words. For example, at a visit to An Giang school for CWD, the research group still saw words like "dumb class", "deaf class" in stead of hearing or visual impairment on a black board. Although only words they cause great pain to CWD (see Case Study II). The above terminology, even when used unintentionally or when widely used in casual sentences or jokes can all hurt a CWD.

In An Giang, in addition to the above terminologies, many people connect CWD with their families' moral values, and which unintentionally creates a distinct aspect of discrimination. At least five people in two group discussions with parents having CWD in Chau Phu, An Giang complained that community members circulated a rumor that "their family lives unrighteous so they gave birth to such disabled children". That illogical blame was primarily concentrated in the families with severe CWD. This morality-related discrimination is more wicked than the above terminologies as it cuts deep into their self-respect and moral values which are so important to the Vietnamese:

> *I don't know why my child is disabled. But people in my commune often talk with each other that it is caused by our unrighteous living. I am very unhappy but I don't know how to explain. I don't want to see them any more.*
>
> (One father has a child with Down syndrome in Binh My, Chau Phu, An Giang)

Discriminating behavior is also manifested in other ways such as keeping away from CWD, not permitting CWD to play with non-disabled children, pushing, beating or even showing emotional indifference to pains of CWD. This behaviour often exist between non-disabled children and CWD, rather than between adults and CWD. All these behavior types are mentioned in discussions with children groups (disabled and non-disabled ones) - see details in the part of children's attitude at school. Surprisingly, they were rarely mentioned in interviews and group discussions with parents, even with parents of CWD or with officers in charge of related sectors/branches.

Discrimination also exists for teenage children and sometimes leads to even more serious discrimination -- self-discrimination. For example, one 18 year old girl in Gia Canh commune has a crippled leg. Names from her friends such as "chipped girl" or their imitating actions make her not dare to show up in front of a strange crowd or cause her to sneak away from their stares. Sometimes she cries in isolation and confusion. She even cried when sharing with the research team about such experiences (see details in Case Study II).

It should be emphasized that CWD who are bullied or mocked, feel very angry but tend to suppress their emotion, hoping everything will pass. But this suppression creates a vicious circle making them prey for more bullying. For example, one grade 4 girl, in Phu Vinh commune, lost one eye. In her class, one classmate called her "blind girl", she was sad, angry and wanted to cry but she could not. She did not share this thing with anyone, even with her parents – the people she loves most – just because she thought that her stories would bore her parents. (FG with CWD aged 10-15, Phu Vinh commune, Dong Nai). When the research team asked her if she could relate a situation in which other people had made her unhappy, she burst into tears as she told the above story.

Ironically, such discrimination and self-discrimination was not seen as an issue in the eyes of adults like teachers, parents, community leaders, and personnel in-charge. All of them assumed that the current society knows a lot about disabilities and therefore have a sympathetic and supportive attitude instead of discriminating against CWD. In a FG with parents of non-disabled children in Gia Canh commune, all denied any existence of discrimination against CWD nowadays: *"No. Today, nobody has discrimination attitude. They are all good."* Teachers at primary schools and secondary schools also stated that there was no discrimination between teachers and CWD or no existence of non-disabled children's bullying CWD. In fact, discrimination is real but beyond adults' knowledge and control. For example, the research group met disabled students at their primary school and their teachers in two different discussions (in Phu Vinh commune). The findings on discrimination are contrary to the two FGs. In the meeting with students, at least three students confirmed that they were bullied by other classmates (pushed, called as "blind one"...). Such situations made them want to cry but they couldn't and they wanted to share with their parents about them but couldn't either. Despite this, no teacher admitted that there was such behavior in their school.

The findings suggested that discrimination actually exists but is out of teachers' observation and control. Even when a student - grade 4 - with mental retardation (often sitting in the class during break times) was beaten by his classmates throughout many terms, but his teacher did not know about it (Phu Vinh primary school, Dong Nai).

Fear and avoidance

Fear and avoidance are a special forms of discrimination in this research, and the most affected groups were intellectually impaired children (especially Down syndrome) or children with behavioral disorders. Even though many people feel sorry for these children, they are not willing to approach or interact with them during individual or communication activities. The reason is that they are frightened of the dangers to themselves because the children cannot control their behavior and they don't know when the children fall ill. For example, one child has mental retardation and behavioral disorder (Gia Canh commune). He has a habit of shaking strangers' knees whenever he sees them (in fact that behavior suggests that he wants to know the strangers' name and does not mean any harm to them). His neighbors often avoid him or politely get rid of him by giving him something (eg a banana or an orange) and asking him to take them home.

That way, they did not have to face him any more. Another example, in Phu Vinh commune, Dong Nai, there is a 23 year-old boy with minor behavioral disorders. Usually he is very virtuous and he can play with other people. But if he has an episode, he can throw rocks at anybody passing by. So everybody is frightened of him to the point when they do not dare to play with him any more. At school, there are students with abnormal actions which meant they left their schools. For example, one 15 year old girl has high-frequency epilepsy. Her teacher did not know when she would get a seizure whereas her parents did not want her to be in danger. They let her quit school instead.

Attitude and support of local leaders

Support from local authorities, unions and staff (at commune and village levels) is very important to ensure the rights of CWD and to partly assist their family with material aid when they are in difficulty. However this type of support is still unsystematic, unfair and unpopular in all communes. Three main supports from local authorities are: 1) Visiting and offering gifts to CWD; 2) Mobilizing charity donation for families of severe CWD with particular difficulties; 3) Implementing policies and laws to CWD. These three forms are helpful to CWD and the families, but unfortunately the implementation of these is not synchronous and systematic, and thus misses many of the disabled children who should have been beneficiaries.

Firstly, almost communes paid home visits and deliver gifts to CWD and families, but this is not on a regular basis. Specifically, commune authorities just deliver gifts to CWD on major occasions (Tet holiday, Mid Autumn Festival), through activities for all children including CWD. Note that the home visits were mainly realized by village officers (village heads, women’s union) but seldom by the commune’s leading officers. Also, such visits were so few and thus not leaving any impression on CWD and their families. Most of parents of CWD and CWD, if they even admitted that they were visited and delivered gifts by commune officers, would answer broadly that ‘we receive gifts in Tet holiday and Mid Autumn Festival” “After a long time, representatives of woman union or village head came to our house”, “Commune officers never came to our house”. In addition, there remain families of CWD who never know about such activities of visiting and delivering gifts: *“since I gave birth to my child, even she is seriously ill and we are very poor but no one cares, visits or deliver gifts”* (one mother has a child with cerebral palsy aged 10, who can not travel by himself or take care of himself). Some parents of CWD in Chau Phu, An Giang complained that this kind of visit is often held on the occasion of a professional team from higher level (such as research, charity or press). And those visited by them are often typically serious disabled children and they were revisited repeatedly.

Secondly, most of communes have programs of mobilizing charity but these programs are still limited in scope and beneficiaries, but not focused on systematic activities so that all CWD in the community can benefit. Each commune often organizes these programs once or twice a year and in each campaign only some CWD got the benefits. For example, according to one leader of Khanh Hoa commune, An Giang, his commune mobilize charitable giving twice a year.: (Mid Autumn Festival and Tet holiday) for with CWD in real difficulties. As such, at present mobilization programs simply target individual CWD and locally, but are not really systematic to benefit all CWD in the community. For example, communes can mobilize publicly donated money, rice, clothes, milk and even some rehabilitation equipment for CWD of really desperate families but none of these activities are ever systematically targeting all CWD in the community.

Thirdly, local authorities have implemented Children Law and related Decrees such as Decree no. 67 (now it is Decree no. 13) for years, but some CWD missed out on getting their benefits because of shortcomings in the identification, reporting, checking, monitoring/supervision and support of CWD. There are badly disabled children who were neglected by their parents and become psychologically confused, but who have never got any attention from local authorities for medical check-ups or treatment (i.e., a 9 year old girl, in Gia Canh commune – in the typical occurrence I). Some children are able to go to school, but they are denied access to school because of they are over school-age or unable to care for themselves (i.e., a 12 year old cerebral palsy girl, in An Chay town, Chau Thanh, An Giang – in Case Study III). There are also children with bad cerebral palsy, always sitting/lying at home, and whose parents are very poor and have to earn their living on a daily basis, but received no subsidy or any special assistance (a 14 year old with cerebral palsy, Khanh Hoa commune, An

Giang). A child with Down's syndrome in Binh Thuy commune, An Giang, although not able to take care of himself or to control his behavior, received no attention and support from local authorities despite the fact that his family was so poor and (his father carried soil on whereas his mother stayed home to take care of him). The mother hoped to get a medical insurance card for him but it was impossible as she could not afford it. There are many examples like that where parents were ignorant of the rights of their CWD and tended to say nothing in order to claim their benefits. As the Law for CWD became effective officially as of the middle of July 2010 and before it came Decree no. 67, the implementation of those legal documents in that manner was not satisfactory. Once again, this pitfall is partially attributable to the shortcomings in investigation, identification, and listing of CWD as beneficiaries.

Fortunately, even though policies can not solve the problems of the parents, their close neighbors and especially hamlet officers are doing positive things for them. According to parents of non-disabled children in Phu Vinh commune, the hamlet leader often comes to visit households with severely disabled children. And especially when the families face big difficulties (no rice, no labor goes to work to earn money), they voluntarily ask for rice from neighbors. Many people come forward to help: *I call support from other ones. I only need to carry the rice bag; every one seeing it will give some rice. Each contributes some and it can become much. Doing like that is to help them* (the hamlet leader, in Phu Vinh commune). Hamlet/village officers are useful information sources and a bridge connecting families of CWD with charity sources and services for CWD (e.g., church-based charity, free hospital check-ups…):

> *They are too poor, stay at home every day and don't know any information about aid sources or charity sources. We have to ask them to register or register for them, and then they can get the charity or aids.*
>
> (One woman in Phu Vinh commune).

However, those typical examples are not widespread: some communes have such examples, but others do not. Such support was more common in Dong Nai than in An Giang.

Role and coordination between local sectors

Currently, activities related to CWD at the grassroots level are integrated into overall programs of caring and protecting children. Sectors participating in implementing CWD's rights operate independently rather than under united coordination. The three main sectors directly implementing the rights of CWD are: education, health and social protection.. There are no clear functional links among these three key sectors in investigation, identification, classification, supervision and implementation of policies for CWD. For instance, in the investigation phase, each sector (education and social protection) performs their separate investigation, using different forms for surveying, reporting, evaluating, and classifying CWD. This inconsistency results in different data on CWD for different sectors (see details in the part of distributing CWD based on social functions).In the mean time, the health sector, the one with professional expertise and competency to define degrees and types of disabilities almost stood out of those entire processes. Such lack of coordination among the three sectors might contribute to the fact that many CWD missed out on getting their benefits (for details see section of role of local authorities).

Other sectors such as the Women's Union, the Youth Union, and the Red Cross Association are primarily in charge of communication, mobilization and organization of social, cultural activities and integration of children into community, but they do not have a clear-cut collaboration and task assignment mechanism to harmonize their activities. Women Union –largely in charge of mobilization and community communication – has the advantage of having its networks at villages and household level. However, its communication style is traditional (one-way) while communication content is mainly about household business, family planning, mother and child health in general, but rarely touches CWD. Particularly, the Women's Union at various levels in the two study provinces lacked a way of effectively enhancing the knowledge of its members about children's rights in general and CWD's rights in particular. Although the Women's Union communicated with its members through the union meetings, personnel from other sectors such as health, education, social protection, and so on were not present at the meetings. The Youth Union had much potential in organizing entertainment and CWD integration activities. But in fact, their role is still fuzzy in promoting activities of integrating CWD into the mainstream society. There is still a lack of activities to integrate the rights for CWD in major social activities of the Union.

Besides the above-mentioned sectors, each locality has a network of collaborators who undertake many tasks and have the potential to coordinate itself among different types of activities at the grassroots level. However, they have not been allocated specific responsibilities with regard to CWD and there has not been any concrete and relevant collaboration mechanism for this group in this regard. In reality, grassroots collaborators are commonly the personnel of the Women's Union, the Youth Union, village health workers, population collaborators and active members in the community. They work under the instructions of the commune steering board and can implement tasks of many different vertical sectors like health care, education, children care, social protection, plus the activities of their own entities. However, much of the work is carried out under the instructions of each vertical sector through a top-down approach and seldom from their own plans. For instance, when a sector implements an activity, the provincial steering board sends official dispatches to districts, then to communes, afterwards to leaders of branches, and finally to collaborators. Clearly under such a management structure, one collaborator can receive many dispatches of guidance from different sectors and branches. There is a lack of task assignment and collaboration mechanism. It is assumed that if all relevant sectors work out a common, general coordination mechanism, the result will be a cut back in much of work that collaborators must currently undertake.

VI. CONCLUSIONS

6.1. Family and Social attitudes and roles

Data base on CWD

Statistics on CWD are not precise and systematic due to the lack of an effective surveying, reporting, and monitoring systems among the three key sectors: health care, education, and social protection. The fact that each of those three sectors employed different surveying criteria means they are likely to miss cases (CWD), and this, in turn, obviously affect the implementation of policies and laws for CWD.

Knowledge on disabilities

Knowledge on conception, causes and classification of disabilities among different groups of study participants are not consistent, inadequate and often reflected their experience or perception of CWD rather than their systematically acquired knowledge on the matter. While children think about disabilities with their real observation or understanding and often associate disabilities with missing or deformed body parts, adults think about disabilities from many angles including economic losses and spiritual damage. Moreover, children tend to classify disabilities based on their physical ability: normal disabilities (unable to walk with an ability to learn) and abnormal disabilities (unable to walk and without an ability to learn). Adults classify disabilities based on severity; causes and the contexts in which disabilities arise; and impairments of body parts/functions. Finally, children do not try to explain causes of disabilities while adults categorise disabilities into nine groups of causes:

1. Malnutrition of fetus;
2. Insufficient vaccination
3. Severe diseases that were not treated in time;
4. Being deserted by parents during first years of life;
5. Accidents;
6. Being affected by dioxin;
7. Due to the use of chemicals in weed killers and pesticides;
8. Heredity (gene change/mutation);
9. Parents do not living virtuously as (“immorally”) so their children are inflicted with disabilities by god (especially with the disabilities group of cerebral palsy and intellectual impairment).

Knowledge on early prevention, detection and treatment of disabilities remains limited among adult groups. Local people (especially CWD parents and carers) are generally passive and do not possess any skill to prevent disabilities at all. Parents of CWD lack knowledge and skills to detect disabilities related to brain damage such as intellectual impairment, behavioral disorders, especially cerebral palsy. Therefore, these types of disabilities are often detected much later than other body and functioning impairments. At the mean time, local people do not care much about early treatment for disabilities: they either delay the treatment through health care facilities until the disabilities get more severe or provide early but cursory treatment based on their experience.

6.2. Health Care and Rehabilitation

Family practices in health care and rehabilitation for CWD

In general the parents of CWD in the study areas did not provide or seek adequate health care and rehabilitation for their CWD, but they did provide CWD with attentive home-care and hygiene. Common health care and rehabilitation practices by parents of CWD in the two provinces include:

Visit at Social Protection Centre for orphans with disabilities in Dong Nai province

- Not taking their children for periodical medical check-ups and treatment;
- Taking their children to private clinics;
- Buying medication and treating their children on their own; rehabilitating their children on their own;
- Being impatient about maintaining the rehabilitation regime even under instruction and supervision of local rehabilitation staff.
- Providing better home-care and hygiene to CWD thanks to their love and perception that "CWD are more disadvantaged than other children in the family".

Barriers for CWD and their families in health care and rehabilitation

Major barriers exist contributing to the above insufficient health care and rehabilitation. These include:

- CWD were prone to diseases, however, their parents lacked knowledge on disease prevention for them so they were often passive in preventing diseases and giving treatment to the children.
- The parents' knowledge and skills in rehabilitating the children remained limited, especially those in An Giang: they either did nothing or rehabilitated the children based on their experience or gave up as they found the problem not improved.
- The parents often lacked belief in their children' progresses so they lost their heart in maintaining the treatment regime for their children.
- Long distances from home to health care centers was another big barrier for CWD to get medical examinations and treatment.
- Poverty and hard work were the leading reasons to the parents' unwillingness to take CWD out for timely medical examinations and treatment or periodical medical check-ups.

Institutional barriers:

The health care sector, despite efforts to boost the provision of health care services for children including CWD (through national campaigns of check-ups and treatment and national health care programs), has not really met the demands and expectations of care for CWD and their families.

The health care system in general is facing the following challenges:

- Lack of preventive services and early diagnosis of disabilities;
- Lack of an effective health care counseling system at various levels, especially in regard to CWD;
- The network of village health care collaborators is large, but they have to undertake multiple tasks assigned from numerous national health care programs and from different vertical sectors including health, education, and social protection.

Rehabilitation services (both at hospitals and in community) remain limited with respect of material facilities, equipment, and human resource. There is either absence (in An Giang) or weakness (in Dong Nai) of a community based CWD component in current health care system. This situation has resulted in a lack of action in the health sector in all the critical areas in which the sector could function to support the CWD in early detection/confirmation of the cases, identification, care & treatment and rehabilitation.

This absence/weakness also resulted in a poor co-ordination and effective work of other sectors such as education and social protection. The system is not effective either in transferring rehabilitation skills (from hospital-based rehabilitation) to families and providing them with adequate supportive supervision. The lack of incentive for rehabilitation collaborators at the grassroots level is another challenge for sustainability of the community-based rehabilitation.

The implementation of the free medical check-ups and treatment for CWD stays restricted due to the lack of collaboration among sectors and unions in doing surveys and mobilizing CWD's optimal participation. Many CWD should have enjoyed a protection policy and free health insurance, however, they were ignored due to the lack of an effective surveillance system in identifying, reporting, and checking CWD at community level.

6.3. Education for CWD

Parents' attitudes toward CWD's studies

Parents' general attitudes in the two study provinces were supportive of their children's studies, but they had difficulty selecting among different education types for their children. Parents of children with minor impairments which still allowed CWD to participate in casual activities with non-disabled children were not worried about their kids' learning at inclusive schools. But those with CWD with more severe intellectual retardation, cerebral palsy, and behavioral disorders, were worried about their education opportunities at inclusive schools because of various concerns:

- Their children did not have ability to care for themselves;
- School teachers/personnel would not have much time to care for their children;
- Their children would be bullied by friends of the same age;
- They did not earn enough money to cover school fees (as the majority of them are very poor). On the contrary, parents of children with minor impairments (and not disabilities related to brain damage) did not show concern about their children studying at inclusive schools.

Barriers from CWD and their families

Although most of parents backed their children going to school, various barriers exist to prevent many CWD from going to school or resulting in them dropping out of formal education. These include:

- Children's severe disabilities and abnormal bodies;
- Distances from home to schools;
- Poverty and parents' impending losses of opportunities to earn money;
- Parents' unwillingness for the children to suffer from hardship at schools;
- Parents' lack of knowledge on kids' educational opportunities and interests;
- Parents' lack of belief in their kids' abilities to learn.

Obstacles from the community and authorities

- There remain many obstacles from the community and local authorities in creating fair opportunities for CWD to go to school. These include:
- Lack of a surveying and education consulting system for CWD;
- Lack of collaboration among authorities, sectors, unions and the education sector on mobilizing CWD to go to school;
- Lack of a supportive and policy consulting regime for CWD;
- The community's acceptance of CWD's working to earn income;
- The people's lack of interest in the rights of CWD.

Institutional education opportunities and barriers

Education activities in the two provinces simultaneously take roots in the three key aspects: inclusive education, exclusive education, and integrated within the social protection system, however, they have not met CWD's actual demands either in quantity or quality.

Inclusive education

While inclusive education is regarded as a common measure that promises to bring education and integration opportunities to most of CWD. However the reality is almost the opposite as most of CWD have never gone to school (when they reached school age) or have left school.

Those CWD attending inclusive education are mainly those with a mobility disabilities or lack of a body part. Other types of disabilities like hearing impairment, visual impairment, behavioral disorders and intellectual impairment make up a small proportion of CWD going to inclusive schools. Besides, the quality of inclusive education is limited due to several factors:

- Teachers not well trained nor given adequate technical assistance for inclusive teaching;
- Lack of supportive and rehabilitation facilities at school;
- Lack of teaching manuals and quality assessment system for CWD;
- Lack of entertainment activities, especially physical education for CWD;
- Incentive regime for inclusive teachers remaining too modest;
- A successful model of inclusive education not established.

In addition a remarkable number of CWD dropped out of school due to the following barriers:

- CWD have to help their parents with domestic chores or even to work for income;
- The distance from their homes to school is too great and being disabled often makes travel harder;
- Their families face hard economic conditions (lack of money to pay for school fees);
- The community and parents still consider children working as a partial solution to their families' inherent poverty.

Exclusive schools

Exclusive schools at present stay modest in terms of number and so only meet the demands of a small number of CWD (mainly those with hearing impairment, visual impairment and some with intellectual impairment). The two exclusive schools (each in one province) have been making efforts to build up their facilities (with accommodation, resting, entertainment, learning and vocational training for CWD), learning and rehabilitation equipment for CWD. However, general challenges for both schools lie in the lack of opportunities for CWD to really integrate into the community, vocational guidance and training, and employment opportunities for them after graduation.

Social protection centers

Social protection centers accept a small portion of CWD, and mainly focus on nurturing activities, but less on provision of knowledge, vocations and life skills for CWD. General difficulties at those centers lie in the lack of material facilities, teaching and rehabilitation equipment for CWD, especially lack of skills among personnel in caring for severely disabled kids. Most personnel working in such facilities performed their work based on their experience but did not get outside technical assistance. Even with Bien Hoa nurturing center – one facility with achievements and experience, was confronting a series of challenges:

- Officers lacked teaching and rehabilitation skills for CWD;
- Lacking instructive documents/manuals for caring and teaching children;
- Lacking a mechanism of CWD assessment and technical supportive supervision (mainly based on experience);
- Lacking stable connections between vocational training and employment opportunities for CWD.

Education opportunities in the community

CWD groups in the community (not the above groups) almost invariably did not have the chance to access education. For CWD of minor disabilities and about to enter primary school, their families and kindergartens play important roles in preparing them for inclusive school. It is not always easy however, because the parents lack knowledge on educating the child while pre-school teachers hesitate in confronting difficulties caused by the children with disability. Those CWD that dropped school do not have a chance of learning anything else, but often “taught themselves” through T.V, radio, newspapers at best, or learning through playing creative games like drawing. There has not been any pattern of care and education support for the severely disabled groups (especially those with cerebral palsy and those unable to care for themselves, those with severe intellectual impairment, and with behavioral disorders). Parents think about sending their children to social protection centers in the province, however, they find it impossible due to the long distances; their love for the child; poor economic conditions; and the lack of knowledge about CWD’s interests, opportunities and difficulties facing the child in those facilities.

A 12-year old girl, not going to school, but good at painting (An Giang)

6.4. Information access

Communications channels

Parents do not often take initiatives to seek information related to their CWD, but passively acquire information from such people as health care workers, teachers, especially personnel at grassroots level like village heads, women union members, health care workers, and collaborators/volunteers. That is the key and most common information channel for parents because of its familiarity and popularity.

Teachers, friends, libraries (books, tapes, disks), and TV, and radio form the main information channels for CWD, but their preferred channels are books and newspapers with typical stories about people with disabilities. As for CWD in the community, TV and radio are their two main sources of information. Those children most enjoy watching entertainment programs such as sports, music and game shows.

Some TV programs currently use “sign language” to increase accessibility for those with hearing impairment. Examples of such channels include HTV7 and O2 TV. Unfortunately, very few CWD can access those channels. Moreover, “sign language” is confusing to CWD and the teachers as it is not standardized nationally.

Most of the channels for parents and CWD do not convey information about CWD-related content such as the rights, responsibilities, and opportunities of CWD. Besides, there still lacks a broad-spectrum system of counseling on the benefits and opportunities for CWD, especially those related to education, health, and social benefits.

Communication quality

The quality of communication at the community level (especially for parents) is limited due to the lack of communication skills among personnel and an absence of post-communication follow-up and support mechanisms. Mainstream communication methods are just the one-way pattern, but often without visual illustrations or interaction with the audience.

On the contrary, the quality of communication for CWD seemed to be more effective in forming critical values for them. The lessons of civil education in inclusive classes; the priorities and protection given by teachers at schools; and especially stories of successful CWD in their studies and careers, through TV, magazines and in real life serve as a strong catalyst to boost CWD’s endeavors to overcome their low self-esteem issues and encourage them to keep trying for the future.

6.5. Public and entertainment facilities

Entertainment activities

Entertainment activities for CWD are primarily folk games involving energetic physical activities and usually held by CWD themselves but without guidance and protection from adults. Apart from exclusive schools, other educational institutions and communities have little entertainment activities for children with mental retardation, severe movement disabilities, and behavioral disorders. Meanwhile, the social protection center primarily focused on nurturing, rather than creating entertainment activities for them.

Besides playing games, CWD watch television, read newspapers, listen to the radio or do activities they like such as painting, collage, and sometimes participating in festivals, social exchanges and visits to schools or communities. But there are few opportunities to truly integrate CWD with non-disabled children in different contexts.

Public services

Architectural buildings, transportation systems, parks, public toilets and entertainment centers in the two provinces are virtually not tailored to the needs of people with disabilities. The only two examples of public services tailored to people with disabilities are a park located in the center of Long Xuyen city, An Giang, with a new public toilet designed for people with visual impairment, and a ticket-free bus for CWD in Dong Nai.

6.6. Vocational guidance and employment

The vocational training and employment for CWD in both provinces confront numerous difficulties in recruitment, vocational training, and job opportunities. Major barriers for vocational training of CWD include:

- The limited number of vocational training centers for CWD;
- Those centers lacking teachers specialized on CWD;

- Long distances from home to a vocational training center;
- Health problems and disabilities of CWD;
- And poverty of CWD family.

In the meantime, employment opportunities for CWD were limited by a series of factors such as the instable job market and incompatibility between the needs of CWD and employers. Although both provinces have some models linking job training and job creation, these are still operated locally, but not systematic and sustainable.

6.7. Values and life skills

Perception of relationships

CWD have a great desire for friendships and feel blessed to have friends. The absence of friendships drives them back into their own world, feeling lonely, empty, and desperate for friends.
For most CWD, family is where they found most comfort and security. They often included neighbours in their definition of family along with friends who lived nearby and even with the pets they loved.

CWD in this study did not have particular comments about their schools, except friendship and group games in which they take part. But kindness, friendliness, and understanding of their teachers formed the most powerful catalyst in bringing them and their teachers closer to each other.

Relations with neighbors are crucial as they form a stable playground and a connection for the CWD with the community, especially when their neighbors had kids of the same age as CWD.. And in those relations, “the neighbors’ kids” played a decisive role in the integration of CWD with their adult neighbors.

Life skills

In general CWD lack communication skills especially when expressing their demands and emotional feelings to others. They tend to suppress their feelings about troubles and unfairness caused to them by other people. Other CWD showed sensitive behavior, which not only helped them to avoid sneers and bullies but also helped them strengthen their existing relations and friendships. Some examples of this type of behavior are: “giving gifts to their friends instead of getting sulky with them”, or “taking initiatives to express their expectations and uneasiness so that their friends will be sympathetic and support them”, always being cheerful and respectful of their friends.

Motivation for CWD

Images or stories about disabled people in real life, on T.V or in newspapers, magazines, books, even on Internet are interesting topics for CWD and often give them more strength to get through life’s endeavors and challenges.

Dreams of CWD

The two major dreams and aspirations of CWD are to continue learning and to get a relevant job and the wish for the disease not to get any more severe. CWD in An Giang are often more open-minded than those in Dong Nai and often wish to get a job rather than wishing their diseases not to get any more severe. CWD in Dong Nai, on the other hand, are often wished their diseases not to get any more severe rather than dreaming of a job or a career.

6.8. Attitude and roles of family and society

Family’s attitude in taking care of CWD

In general parents tend to treat their disabled children as the most disadvantaged family members, thus often giving them more car and attention than other children in the family. In wealthy families where there maybe more people staying at home, CWD are cared for more attentively than those in poor families with fewer members of their family. A few children do not receive protection and care from parents, which caused them to feel lost and empty and tend to seek comfort from outside their family.

Parents and grandmothers are the main care-takers for CWD. They are sources of great encouragement and security for CWD. Other relatives like uncles, aunts, and siblings undertake a smaller part in caring CWD. Siblings mainly spend time playing with CWD while other members support the parents by taking CWD to school and to medical check-ups. In some rare cases, relatives provide some financial aid, or feed the children.

Attitude at schools

Teachers and heads in inclusive schools pay much attention to creating education opportunities for CWD, teaching them, and protecting their rights. However they have not made significant efforts in creating a close connection between schools and families.

Generally, children without disabilities tend to feel sorry for their disabled friends and help them with their school work as well as with daily activities. Three common supporting patterns are: 1. Support in study (giving more instructions, assisting in homework, lending study equipment); 2. Support in playing games (e.g., carrying a CWD on the back, letting a CWD play the same game regardless of her/his playing ability); 3. Protecting a CWD when he/she is bullied by others.

There still exists stigma and discrimination among a small portion of I children without disabilities toward CWD, especially those with mental retardation and visual impairment. However, the phenomenon often disappears quickly and seldom reoccurs if the school teacher is able to intervene in time. Otherwise, this lack of acceptance can cause long–lasting emotional pain CWD.

Community’s attitude

The community’s main attitudes towards CWD are affection and spiritual support. In many cases this attitude is manifested in terms of material support or protective action for CWD. Teachers, friends and neighbors are the closest people to CWD and have most opportunity to share with them.

Obviously discrimination still exists around CWD and their families in many forms (speech, lack of eye contact, avoidance or bullying actions). This sometimes creates long-term stress or psychological damaging effects for CWD. These kinds of discrimination appear in all contexts and classes, however they are more common among groups of children (between CWD and normal kids) because they come into more frequent contact with each other through learning and playing than with adults. Discrimination can lead to “self-discrimination” and the latter form of discrimination is often more serious because it tends to isolate CWD from the outside world.

Unfortunately discrimination and self-discrimination are not seen as critical issues in the eyes of adults: teachers, parents, community’s leaders and staff of authorized sectors and unions. They all have the tendency to think that nowadays society is much better informed about disabilities and therefore has a sympathetic and supportive attitude instead of discriminating against CWD. Unfortunately this is frequently not the case and the result of this dangerous subjective viewpoint can mean a lack of care for psychological problems of CWD.

Attitudes of local authorities

Support from local authorities, unions and staff (at commune and village levels) is very important to ensure the rights of CWD and to help assist their families with material support when they are in difficulty. This support however it is still unsystematic, unfair across all the communes. The three common forms of support from the local authority are: 1) organizing visits and giving presents to CWD; 2) calling for donations for families with CWD and especially those in difficult situations; 3) implementing the policy and law for CWD. These three forms are meaningful to CWD and their families. Regrettably the implementation of such support is not uniform and therefore leaves many CWD who should have been received benefits unsupported.

Roles of local mass organizations and relevant agencies

Nowadays activities relating to CWD at the grassroots level are integrated within the overall child-care and protection activities. The sectors and unions taking part in implementing the rights of CWD usually act independently without any overall coordination.

The three main sectors directly implementing the rights of CWD are: education, health care, and social protection. However these sectors generally act independently of each other and it is hard to see any communication between them when investigating, identifying and classifying CWD in order to implement rights for them.

The Women's Union, the Youth Union, and the Red Cross largely take part in communication and public awareness raising campaigns, calling for action and organizing cultural, social and inclusive activities. But these agencies lack an overall common system for collaboration and task-assignment for implementing the rights of CWD.

In addition to these above three main sectors, each commune has a network of collaborators all undertaking multiple roles and with the potential to coordinate their different activities. However, they do not have a clear-cut guidelines for responsibility and collaboration.

VII. RECOMMENDATIONS

7.1. Policy-makers

Surveillance System

Strengthen the database on CWD through enhancing collaboration among key stakeholders in surveillance system:

The system of discovering, reporting and supervising CWD should be strengthened towards a multi-level, multi-sectoral, but united entity under an overall coordinating agency. It is necessary to establish common criteria for these processes and a general coordination among those closely involved sectors such as social protection, health care, education and key mass organizations (i.e., women`s union, youth union). Also, this system could be strengthened in a way that several concerned sectors (health, education and child protection) will manage and use the same and regularly updated data base on CWD through the shared reporting systems for specific sector interventions.

The personnel who directly survey CWD should be carefully trained in order to standardize the surveillance methods. They should also receive regular and quality technical support from higher levels to satisfactorily fulfill the tasks. The inter-disciplinary exchanges (among education, health care, social protection) through meetings or workshops and field visits are crucial in reinforcing the implementation processes and ensuring the quality of the data.

The survey of CWD just piloted in 7 districts of An Giang (under the coordination of the provincial social protection center) promises a practical model. It should, hence, be essential to soon obtain an elaborative report and lessons learnt from that survey for replication on the entire province. Dong Nai and other provinces could also take this survey as reference for their application.

Health Care

Strengthen the roles of the health care system in counseling and communication activities

The regular healthcare programmes/campaigns of hospitals or national health care programmes should integrate a component to educate the community about the causes of disabilities, disabilities classification, prevention and early intervention of disabilities. Such programmes should develop education materials tailored to local needs and habits, using locally-known illustrations, easy-to-read materials to fit a wide variety of audience. The health sector should integrate counseling on CWD at all public health-care facilities and also have appropriate IEC materials on CWD issues with intended messages.

Increase the coverage and technical support for community-based rehabilitation

Establish or strengthen the CBR for An Giang & Dong Nai, where the CWD community base component is still either, a blank (An Giang) or weak (Dong Nai). This CBR will allow the locality to have a better quality data and information collected, to be shared and used. This CBR will also work as a starting point for collaboration between several involved sectors, in which, all types of support and possible interventions to the PWD will be implemented at community level.

The rehabilitation system should also extend its rehabilitation and counseling services for different kinds of disabilities, but not just focusing on movement disabilities. All rehabilitation facilities should have manuals for the staff and care-takers to practice the techniques. Also, the counseling should always be with culturally-adapted IEC materials and illustrations.

A class of children with disability at Social Protection Centre for orphans with disabilities in Dong Nai province

Rehabilitation centers at hospitals (district or province) should play the leading roles in the district or province for technical transferring to lower levels through training, technical support to community, especially at the household level. It is necessary to have periodical reports about these activities to timely draw experiences and for readjustment. The field visits (supervisions) and technical support for grassroots level should be more regularly implemented (every month or quarter) instead of once or twice a year.

During the supervisions, the technical personnel in charge should provide detailed and feasible recommendations for local rehabilitation staff to improve and update their skills. Excellent local staff and successful households in rehabilitation effort should be recognized as typical examples for replication.

Transferring rehabilitation techniques for family while reinforcing supportive supervision at households

Local rehabilitation personnel should only be a catalyst (facilitators) to boost community-based rehabilitation as they alone could not do rehabilitation for all CWD in their community. Hence, the programmes should make effort to transfer rehabilitation skills to household care-takers while promoting the roles of facilitation and supervision among the local rehabilitation personnel to ensure the quality of the transfer.

The household-based supportive supervision should provide specific and easy-to-follow recommendations to parents or care-takers. There should be a monitoring notebook which records all progress of the CWD together with specific advice/guidance from rehabilitation staff and commitment of the family. The programmes should also utilize successful rehabilitation households in the community to set examples for other families to follow.

Education

Teachers of inclusive education have gained some experiences on teaching CWD, especially those with mentally disabled children. But these teaching experiences have not been systematic or standardized. Therefore, the education sector should have research at a macro level to systemize and adjust these experiences before sharing them on a national scale. The sector should also bring into play the sympathy and the responsibility of teachers and also equip teachers with active and friendly teaching methods which are suitable for all kids.

Communication

The “sign language” dictionary for the disabled people should be standardized so that CWD nationwide can understand each other. Television or audio programmes should include sections for CWD, even reserve a separate counseling session for disabilities of children. It is also necessary to update the recreational activities of CWD on these channels so that they can entertain and have plans for participating in such activities of their preference (i.e. sports or games).

Public and Entertainment Services

Architecture buildings, traffic systems, parks, public toilets and other recreational areas should have built-in functions for the disabled.

Vocational Training

The vocational training activities for CWD should be included in the general development strategy of the province. Therefore, the exclusive schools should provide inputs in development of such strategies regarding vocational training and employment opportunities for CWD (practically to the department of Labor – Invalid and Social Affairs).

7.2. Health care providers

Health care professionals directly implementing national health programmes/campaigns or working at public health facilities should be provided counseling skills and enough information about the rights and opportunities for CWD in the province and nationwide. It is necessary to build the image of "every healthcare provider is a friendly counselor" to eliminate the wide-spread prejudice in the community about health care officials that "health care officials are indifferent, just carelessly checking, then giving the medicine to my kid". They should also play as resource people to refer parents or care takers of CWD to relevant sources when needed.

7.3. School administrations and teachers

Inclusive School

All inclusive schools should be equipped with inclusive teaching manuals and materials including tools for the entrance assessment as well as the progress tests throughout the schooling process where not available.

Inclusive schools should obtain rehabilitation tools and sport tools so that all CWD could take part in and keep fit. Games for kids should also be diversified and suitable for CWD of different types.

These schools should also organize extra sessions for CWD and pay commission for the teachers who teach such sessions. Schools should recognize and award teachers excellent in teaching CWD. These schools should set up friend-help-friend models and based on these, encourage kids to set up groups of cooperative friends to help the CWD travel to school, study and support them when they are in need.

Schools should do more to establish stronger relationships with families in making cooperative plans to teach CWD at home and at school. Besides parents' meetings at schools, teachers should visit CWD families (occasionally) to get to know their family contexts and through which motivate them to further study.

Exclusive School

It is necessary to standardize the entrance assessment, lesson plans and skills to cope with different types of disabilities for the teachers. The orthodox manuals and reference materials should be available for the above purposes.

Reinforce technical supports from seniors and from higher level while promoting cooperative learning among the exclusive schools (through school visits, conference…)

Schools should extend consulting services on early intervention to the community at large, but should not wait for local people to come for advice (because they are commonly passive in seeking professional advice). To this regard, the schools should consult the provincial counseling and communication center for child affairs to elaborate the most effective way.

The exclusive schools and sponsor centers should give CWD more opportunities to take part in the outside environment by organizing exchanges for them instead of inviting visits at their schools.

7.4. Social protection centers

These centers should also have plans to improve the skills of caring and teaching CWD for their staff. These skills include nurturing, teaching, rehabilitating and coping with CWD's disabilities and health conditions. The centers should also diversify their recreational activities and increase opportunities to include CWD with outside communities.

7.5. Local authorities

At commune and village levels:

Review the list of policy beneficiaries and readjust the policy implementation at each village and commune for the forgotten CWD

As this review involves many sectors and organizations such as social protection, education, health, and important unions/mass organizations like women union, youth union…, an inter-disciplinary steering board should be set up right at the commune and village level with a specific task assignment for every sector to undertake the task.

The commune authority should hold campaigns to encourage families with CWD to raise questions or concerns to the village/commune steering board. This will avoid unfairness and missing cases.

Upon having the findings of the review, each and all localities should readjust the policy implementation accordingly. They should consider compensating for the periods when CWD should have received the benefits.

Support families with CWD in preparing them for schools or encouraging continuing education:

For CWD preparing for grade I, local authorities should intervene so that these children will not be denied to learn at kindergarten or preparatory classes. Besides the teachers at kindergarten, well-literate CWD at community should also be utilized to teach CWD.

This way not only saves money and human resource but also promotes the self-esteem and the value of CWD in the community. In the long term, the teachers at kindergarten should be equipped with knowledge and skills of early intervention (education before grade 1) and they can guide the parents of CWD to do work together.

With the CWD quits school, it's necessary to encourage their family to continue their learning (if the CWD can learn more) and/or give them vocational training. It's very important to build a model of a successful CWD after vocational training (should have specific examples in the community).

It's necessary for the community and the local authority to check the list of policy beneficiaries especially the children preparing for school and children in the poor families to fairly apply the policy of school fee exemption/reduction.

The local authority should raise their voice against the fact that some families make their children quit school to do domestic chores or farming work. In addition, they should raise awareness for local people about the rights of CWD including the right to develop and to access school. They should also encourage these people to ask for their children's rights instead of just waiting for information or support from other people.

Diversify entertainment services for CWD

Besides the folk games, local authorities should have recreational activities and exercises suitable for different types of disabilities of children, especially for the mentally disabled group. Inclusive playgrounds should have tools or sport equipments for CWD to promote their activities in those settings.

At provincial level:

Standardize existing social protection centers

The number of social protection centers are too few compared with the real demands. However, new building of such centers is infeasible due to the lack of material facilities, human resource and finance. While it's impossible to increase the number of these centers in the near future, local authorities should focus on standardizing the existing ones; targeting the integration of: nurturing, rehabilitation and teaching life skills for CWD. The Bien Hoa nurturing center for CWD and orphans is a suggested reference model.

Mobilize internal resources from vocational guidance and training system

Provinces should evaluate their vocational training system and employment opportunities for CWD in the local area. Listing and assessing the training needs of CWD, ability of vocational training facilities to meet such needs, and demands for human resources of enterprises within the provinces should be done thoroughly. One of the outputs of this assessment should be the commitment of enterprises to provide CWD employment opportunities after vocational training.

In addition, it's necessary to have media campaigns mobilize the community to send their CWD to vocational training according to the existing supporting policies.

The campaigns should emphasize the long-term benefits of giving CWD vocational training and seeking a job afterwards. Examples of success stories in vocational training and finding a job in the locality should be widely recognized to create the belief of community.

Some models combining vocational guidance - training and creating job opportunities in the two provinces should be considered as the primary success and the premise for lessons learnt for better and more sustainable cooperation and alliances.

Integrate mainstreaming CWD into government programmes and projects

Provincial authorities should see CWD as mainstreaming components in overall development programmes or projects. Relevant legislation/ guidelines should be developed accordingly to support and mobilize participation of mainstreaming CWD in the government programme/ projects.

7.6. Grassroots collaborators

Currently health care collaborators at grassroots level are overloaded with work while still having to communicate with a large audience. Therefore they should be equipped with effective communication skills (for behavioral change communication) and time/work management skills.

It's necessary to equip these communication staff with effective communication skills, methods of collecting data and of assessing people's needs of information. They also need to be trained on planning, implementing, and evaluating communication activities, and particularly knowledge on CWD and their rights and available benefits/opportunities.

7.7. Parents and care-takers

The first most important recommendation for parents and care takers is to alternate the habit of passively receiving information from others. Communication campaigns should focus on encouraging community members to actively seek information and ask for their children's rights instead of passively waiting for information or support from other people.

Health care and rehabilitation

Increase knowledge, enhance skills and create belief of parents and care takers in taking health care of and rehabilitation for CWD

Communication programmes should provide information to parents or primary care-takers about the types of disabilities and rehabilitation techniques. Step-by-step all needed skills for rehabilitation and signs of progressing or relapsing during the actual rehabilitation should be communicated. It is necessary to focus on the benefits of rehabilitation and the potential losses in the absence or discontinuation of rehabilitation.

Creating belief for the family in doing rehabilitation for CWD by showing them the progressive signals (through home visits). Because of this, during the process of guiding rehabilitation we should guide them from easy to difficult, and from a little to a large amount, so that parents and CWD could follow and get used to using them.

Families should be educated on disease prevention, home-care, and hygiene for CWD including examples of good care already in the community to share with other members. Mothers and grandmothers of CWD should be the target audience as they are the primary care-takers of CWD in the family.

Also promote the following practices among parents and care takers to ensure quality healthcare and rehabilitation for CWD:

Taking CWD for regular medical check up (i.e., every 3 month) at public health centers and for free check-ups during health care campaigns.

Not buying medicine for CWD without advice and prescription from health care providers.

Seeking advice and information at a public health facility on health care and rehabilitation for CWD, but not using unverified folk experience for these purposes.

Strictly following rehabilitation for CWD proposed and instructed by responsible personnel while regularly discussing with them about progress, challenges, and plans of actions to optimize the exercises. Coming to the nearest health center for advice and information whenever having questions about the health status of children.

Instruct parents/care takers on making rehabilitation tools from existing cheap materials and on time management

Because most of the people are so busy and so poor, programmes should guide them to make rehabilitation tools for CWD from cheap materials available within their reach. In addition, guidance on the skill of time management (it’s possible for them to go to work at daytime and to do rehabilitation for their kids in the evening), or guide other members of the family to do exercise with CWD (at different points of time according to the schedule of each member) should be provided.

Education

Raise awareness among parents and care takers of education opportunities and the need for education:

Raising people’s awareness about educational opportunities for CWD, and early interventions for them to prepare for the school.Emphasizing the advantages of giving education to CWD as well as the disadvantages if they don’t go to school or quit school early. Kindergartens and primary schools should have counseling units on education for preschool-aged children.

Establish a model of caring among families with CWD

The group of children with serious disabilities usually requires special caring and educating because most of them cannot take care of themselves, cannot learn letters/words, and even cannot communicate.

Many families have to assign at least a person to care for them. It’s necessary to consider a model in which some families having CWD (these families must be close to each other) put these CWD together and then take turns to care for them. However, this relates to the skill of caring and coping with different types of disabilities and therefore they must be trained. In addition, they could apply the small-credit loans to assist household productivity at the family so that they will have time to take care of their children while still able to work.

7.8. CWD

At inclusive schools:

Besides inviting the individuals and agencies to visit and exchange with school pupils, the schools should organize visits for the CWD to exchange with the outside communities directly related to their life. These include schools, markets, social activities. If these schools are short of money, they should appeal for a donation or submit proposals to local authorities or the donors.The vocational training activities for CWD should be included in the general development strategy of the province. Therefore, the exclusive schools should provide inputs in development of such strategies regarding vocational training and employment opportunities for CWD (practically to the department of Labor – Invalid and Social Affairs).

It’s essential to integrate the knowledge on CWD within the inclusive education system through civic education lessons and outdoor activities. Schools should update books, newspapers or news relating to CWD especially about stories of successful CWD and typical examples of help and support between friends, teachers and community members with CWD.

At community settings:

Organize social exchanging events between CWD and children in which CWD themselves play as key organizers and facilitators. Integrating some small dramas about CWD (children write the plot and act themselves) in such events is necessary. This kind of exchange can be used for many groups of CWD (inclusive, exclusive, and community).

At social level:

Communication programmes, especially mass media, school-based and community-based activities with the participation of CWD should orient CWD towards their integration into the mainstream society, but not towards self-isolation. To do this, besides the respect for friendship, the close relationship with family and neighbors (as it is now), CWD must be equipped with other social skills like assertive communication including expressing their demands and concerns; communication skills; skill to establish and utilize social relationships (which include teachers, friends, neighbors, and other people); skill to deal with some situations (when being laughed at, or bullied…); skill to do teamwork with other kids; the skill to plan for their future; especially self-esteem; the belief on their own power; the will and effort to make progress.

7.9. General public

Establish social norms in treating CWD

Media programmes should focus on building the image of “CWD also can do things that the other kids can” instead of just “feeling pity for” and “alms”. To do this, these programmes should also honor the value and the abilities of CWD in various fields such as good schooling performance, braveness, success at work… instead of focusing too much on the physical pain, diseases or the spiritual impairment which CWD and their family have to suffer.

Absolutely “say no” to the attitudes and behaviors discriminating against CWD and the disabled people in general. In this aspect, the educational institutions and the community have to educate their members about the signals of discrimination and stigma and positive social norms in treating CWD. We should appraise the excellent models in implementing these norms in the communities and the schools.

Journalists and personnel working with media should be reoriented towards stigma-free media for CWD. Workshops and a technical working group (through either online or regular offline events) to brief or update on CWD issues should work to this regard. Also, the technical working group should serve as a “community watch” to identify and propose remedy against any signals of violating “CWD stigma-free” regulations on media.

Increase multi-sector cooperation and collaboration in implementing the rights of CWD

Provinces should reestablish multi-sector relationships in ensuring CWD’s rights. The three main sectors directly implementing these children’s rights including education, health, and social sponsor should cooperate during the process of research, finding, classifying CWD as well as supervision of implementing the rights and policies for CWD (See detail in the recommendation to SURVEILLANCE SYSTEM).These three sectors all have plentiful collaborators at the grassroots level, however in the near future it is necessary to have inter-disciplinary instead of vertical guidelines to reduce the burden for the collaborators.

Women`s union, youth union and the Red Cross unions play major roles in communication and organizing cultural, social and inclusive activities for CWD, however, it is essential to have a collaborative and clear-cut task assignment mechanism for each sector in integrating communication and implementing the rights for CWD.

The collaborators at the grassroots level play a pioneering and crucial role in communicating with local people and discovering violations of CWD’s rights. Therefore, it is necessary to have a mechanism of regular and reward-oriented technical support and supervision in order to bring into play the enthusiasm, responsibility, and quality performance of these personnel.

Apart from that, some important sectors (health, education, social protection) should all set up a counseling system on the rights of CWD (or integrate it within their existing counseling services) and extend the coverage to the grassroots level through networks of collaborators.

7.10. Communication channels and strategies

Communication channels should be tailored to different target audience. Workshops, mass media, and advocacy campaigns at national level should be more realistic. Short-training courses and regular meetings within schools or hospitals/health facilities can be practical to share knowledge and update skills for school teachers and healthcare providers. For parents and care takers, communication through grassroots collaborators (women union, village health workers, red-cross staff…) should be more appropriate. As for collaborators, on-the-job training plus short-training courses and regular technical support should be practical. Mass media and public events and campaigns should be appropriate for the general public.

For CWD, school and community settings should be ideal places for educating them on CWD issues. Besides integrating materials within school curriculum, outdoor activities (games, community events…) should also be appropriate to engage their participation.

Communication programmes should capitalize on the existing knowledge, skills, belief, and practices of different targeted audience and reconstruct them based on the newly-effective law on CWD. The programmes should also take into account cultural and geographical aspects as people in the two provinces have different views on disabilities, especially the causes and classification. These notes should be applicable to different audiences: health care providers, school teachers, local collaborators and CWD.

For all except (policy-makers), it is essential to develop communication materials such as leaflets, booklets with pictures and attractive illustrations (for parents/care takers, and CWD), and technical manuals for school teachers, health care providers, and collaborators. Communication through small groups, using pictures, dramas, problem-solving…are effective ways which people can use to enhance their communication effects (especially for parents, collaborators, and CWD). Using images, real stories, flip chart, Q&A or dramas… should be seen as key tools to mobilize community participation and to effectively convey needed messages (especially for the children) about the disabilities. The programmes should take advantage of their learning and working habits (time, venues, and learning styles) to optimize their learning abilities.

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ANNEX

Annex 1: Case study I: The girl with dog's habits and her learning opportunity

Linh – a 9-year-old girl in Gia Canh commune, Dinh Quan district, Dong Nai province

Context of the case

Gia Canh is among the poorest communes of Dinh Quan district in Dong Nai province with scattered population. People here live mainly on cultivation on burnt-over land. Many households who do not have cultivating land have to work for those possessing large land areas and have this employment as major source of income for their family. The income of at-most 50 thousand dongs/person/day (including meals), however, is sufficient only for most basic needs. It is, therefore, a luxurious thing for such poor families to take their children to periodical medical checkup in the clinics and health service centers.

Regardless of other types of health conditions, child disabilities have emerged and become a pressing social issue in Dinh Quan district in general and in Gia Canh commune in particular. There is rather high concentration of disabled children in this area. According to some parents with disabled children, there are, on average, 10 children suffered from at least one type of disabilities in a hamlet. Among the disabilities, retardation and behavioral disorders are most severe ones because the suffered children and their families faced numerous challenges such as long-lasting poverty, lack of medical care, insufficient access to information and most importantly, the helplessness of people who have to, day by day, witness the plight of those disabled children.

The plight of Linh

There is a girl, aged 9, who was ignored by parents in her early years of life and has now developed dog's habits. She should be able to learn and develop as a normal child but she has not had the opportunity to do so.

Her name is Linh. Her house is in Gia Canh commune, Dinh Quan district, Dong Nai province.
Linh did live with her parents in the first three years of life in a temporary tent in a burnt-over land area which is around 2km from her grandparents' house. Every day, Linh's parents went to do farming, leaving her in the cage with little food and a bottle of water. She ate when being hungry and drank when being thirsty. Her mother came home during the lunch time to feed her in a hurry manner and went back to work. Grandparents rarely came to visit her. Most of the times, she was with a dog at home.

Lack of love and proper care from parents might have resulted in the development of her habits which she learnt from the dog. When she was three years old, the father suddenly sent Linh and his son who was learning to change from supine to prone position to their grandparents with a complaint: "There is something wrong with Linh. She acts as a dog. Please help me take care of her". Linh was then just able to pronounce sounds like "ba, bà (meaning father and grandmother)". One month later, Linh's mother left home and has not come back or sent any information since then.

Having sympathized with the poor father, the grandparents made a temporary wooden house which is over 10m from their house for Linh and her father. This is a low-roofed and wild wooden house. What was observed by the research team in her house includes a simple wooden bed, a bamboo screen failing to cover the door properly, a three-leg stone oven, a pile of old clothes and an ashy brown mosquito-net.

Linh's father works as a mason assistant to earn the daily living but he is sometimes unable to support himself. Linh and her brother often have to rely on their grandparents and uncle (who also has two children) for meals. Though Linh can survive day after day thanks to such meals, she actually lives a life of an eccentric and crack-brained child as viewed by her relatives and neighbours.

At the first look, Linh is quite quick-minded. Her appearance is rather similar to normal children of the same age except she is as bony and pale as a leaf. She still plays with other children in the hamlet. She can hear and understand others. She knows her name and more importantly, she can follow such instructions given by her relatives as eating and discharging the dog, etc.
However, when no one is home to take care of and play with her, she shows abnormal behaviors which worry relatives and neighbours. She plays, sleeps and eats together with the dog. She jumps into the dog to breast it, then rakes the ground to build nest like the dog. Linh sometimes snorts and grinds her teeth when she gets angry and strongly hits the smaller child (a one-year-old child living with Linh's grandparents), leaving a swollen area on his head. Linh's grandmother told us like this:

She breasts as same as puppy. Sometimes, she is found sleeping with the dog. She occasionally disappears for hours. We looked for and found her raking the ground in the garden to build nest and staying there in the same way the dog does. We could not find her in the house. She only answered after long call from me. I found her staying like that when I reached the place. At times she raked the ground to build nest under the bed just like the dog.

There was a time when Linh went to do farming with her aunt. While focusing on the work, the aunt failed to pay attention to her. After a long search, the aunt found Linh being curled up in a soil hole dug by her small hands. It is a habit of Linh to dig and sleep in the hole in the field.

She also eats in a weird manner. Linh does not want anyone, even her brother, to be with her while she is eating as she is afraid that her food might be taken. Linh eats in a clumsy manner. She often lowers her face up to the bowl to eat and refuses to use spoon (when she eats alone), which causes food and rice scatter around. Linh does not know how to use chopsticks like other children (even though she was instructed by her relatives). Linh sometimes is not able to distinguish food for people and food for animals. She occasionally eats excrements or pig's food.

Some people say that she is haunted. Her relatives think that she is an oddish and crazy child who cannot be educated. No one ever thinks of sending her to school. No one encourages her to go to school. She receives no support from the local government.

In the view of the research team, however, Linh can learn and change in a better way. According to her grandparents, when she just moved to live with them (when she was 3 years old), Linh often showed the dog's habits (This sometimes happened every day). In such cases, the grandparents shouted at her or beat her with rods. Gradually, she felt scared and rarely repeated such behaviours. She now "shows them from time to time only" (said her grandmother). When she was three years old, Linh could only say sounds like 'ba, bà'. She can now communicate better, express her feelings, her sadness and happiness, and play peacefully with other children under adult's supervision. Therefore, there is no ground for her to keep staying at home and then being shouted and beaten by her grandparents and uncles whenever the "craziness" comes.

Join hands for action

Upon visiting Linh's family, the two officers of UNICEF and the research team decided to do something to help Linh go to school. This is a feasible task as Dong Nai province has around 20 child protection centers including one for orphans and children with disability. Most of children there suffered from intellectual disabilities, behavioural disorders and even autism. Such children have been properly cared and shown clear progress. Therefore, why cannot Linh learn in such a place?

Right after the last meeting in Dong Nai province, the research team presented Linh's situation to two leaders of the Provincial Department of Social Protection. They expressed their sincere sympathy and agreement to coordinate with the Child Protection Division of Dinh Quan district to have further understanding of Linh's case.

Discussion:

Some significant points of concern can be drawn from Linh's story. First of all, it is the ignorance and improper care of the parents during first years of the child. In this period, the care and education by parents are essential to the formation of the child's personality. Unfortunately, Linh received such care from a dog; and consequently, she developed the dog's characteristics. Secondly, the social workers at the locality were not whole-hearted enough to discover her situation and to provide timely interventions and encourage her to go to school. The local government at commune level and concerned authority did not pay attention to her psychological development and abnormal behaviours. Thirdly, the policy on children with disability has not been strictly implemented at the grassroots level, which results in unfair treatment and even violation of the right for development of children with disability. Particularly, in Linh's case, her mother left her living with the father who is not able to take care of the child. Apparently, she has to live with her grandparents and uncle as part of family relationship in the community. However, it is important to mention that her grandparents who are now over 80 years old are not able to work anymore. Her uncle and aunt live a hard life (mainly on farming) and have to bring up their two small children too. With all such factors, Linh is eligible for social protection (as specified in Item 1, Article 4 of Decree No.67). Accordingly, she is entitled to monthly financial support and will be brought up by a social protection center in the province.

Linh is just one case. Other children may have same situation. Therefore, the local government and concerned authorities should pay attention to the review and application of the protection policy for such children.

Annex 2: Case study 2: A girl with disabilities obsession
Gia Canh commune, Dinh Quan district, Dong Nai province

From the words of contempt

The term ‘disabilities’ has become popular through mass media, research reports, legal documents and policies and even through the daily stories of people in many provinces in the country. It is, however, still unfamiliar to people in Gia Canh commune. They have long associated the disabled children with things like “innate disease” or “orange disease”. Children who suffered from movement disabilities are generally named as “crippled”, “lopped” children or children having defects in legs and arms. No one can ever know that such words of contempt have left behind the heart-rending passions which cannot always be eased by tears. Thuy is one of the cases.

To the obsession of disabilities

In the past eighteen years, Thuy and her family have experienced hardship in the hope for balanced legs for the girl with charming smile and lovely yet sad eyes. When we came to visit her, she was seating with dazed eyes and tried to avoid looking at the eyes of people in the research team. At her sitting posture, no one can realize her defective legs. When asked “What is the matter with you?” she did not say anything about her disabilities except “I have defect in the legs”. When we asked her to stand up, she hesitantly followed. I held her hand and was about to lead her but she drew her hands back and refused to walk. I asked her “Why don’t you walk?” She said “I will fall down”. How do you move in the class? She said “I do move but I have to lean on the left knee” where the leg is gradually getting smaller and shrunk”. We then realized the reason behind such hesitance.

Thuy said that people who sympathized with her and her family treated her as a normal child with sincere and sharing attitude. They do not absolutely mention the defect of her leg and never ask about that even. She wishes to receive their visits or to play with them. However, she is also surrounded by many people with spiteful tongue. And such words of contempt as crippled child or the child with defective legs come from that. It seems to be not enough to them as they even imitate her walk right in front of her. Not only adults but children also do the same things. Sometimes her classmates may accidentally or deliberately push her down, making her feel sorry and pressing without uttering a word. She, therefore, never joins the collective games with her peers.

Thuy’s mother told us about a case when she was selling goods in front of the house, a group of youths found her pretty and teased her: “Do you want to be my wife?”. What is sad was that when she stood up and walked just for few steps, they stopped teasing immediately and left.

Such things have happened more than once and become a painful thorn stabbing her heart and hurting her spirit – a chronic wound. The obsession seems not to ever disappear. Because she even wards off us whom she knows for sure are on her side. Right after the interview ended and when all friends left, she sneaked to the rear door and quietly left. It seems that she is trying to avoid eyes and words which used to be an obsession to her. She could not talk to anyone, just felt sorry and cried. She sometimes sat alone thinking a lot about the past and the future: “Will I be able to get married?”; “What will I do to earn the living?” She could only ask her mother. After enormous thoughts, she eventually asked her mother: “Mom, why does this happen to me?” The mother, being wet with tears, answered that “I don’t know why. You were already like that when you were born” Then, “Mom, what can I do?” “I am not sure; you can be a tailor”. And a dream arouse in her mind: in a very near future she can…. and she can do that thing.

Unfortunately, although she is 18 years old and almost finishes the high school, she has not really participated in any training on tailor. The dream is still far-away from Thuy.

Comments

Thuy’s story suggests three aspects which are closely associated with children disabilities. Firstly, it is the community’s discrimination (being expressed in the words and actions) towards disabled children. This situation is very popular in the research area although there has been clear sign of decrease in the past years. Unfortunately, the community’s discrimination often results in the self-discrimination which is more severe. Because of the self-discrimination, many children confine themselves at home or in the class and limit all the contacts with their peers and the community. In short, they live in the world of complex and thus loose the opportunity for development of social and life skills. One of the interesting findings of the research is that disabled children are not well-equipped with communication skill, life skills including the skill for self realization of personal value, interpersonal skill and problem-solving skill. I should think that if they are provided with such skills, many of them will not confine their sadness. Instead, they will find way to ease the concern by sharing it with close friends, parents, brothers and sisters, and even teachers.

Annex 3: Case study 3: A girl with the efforts for recovery and the eagerness for school

12 year-old girl, in An Chay town, Chau Thanh district, An Giang province

First months of immature life

Hieu Nhi was born after less than 7 months staying in her mother's womb. As she was too young, she was not able to cry right after the birth. Doctor had to inject stimulating medicine and kept her in the incubator for a week before she could go home. Her development was very slow. She weighed less than 2 kg when being eight months old. As she was still able to move her arms and legs, her mother thought that she was in normal condition. A neighbor accidentally discovered that her two feet always stretched out, which was obviously different from normal child. She was diagnosed as having cerebral palsy in the Physical Therapy Department of Long Xuyen General Hospital and treated there for the whole first 4 years of her life.

Efforts for recovery

In the first 4 years of treatment, mother took Hieu Nhi to the therapy place every day. Her grandmother sometimes accompanied and stayed to take care of her as her mother had to work. The mother took her to the place even in rainy and cold days. The doctors there directly treated her and instructed her mother and grandmother also. They gradually became familiar to that work.

When she was 4 years old (in 2002), Long Xuyen hospital introduced her to the Trauma and Orthopedic Center in Ho Chi Minh City (at No.1A, Ly Thuong Kiet street) for leg operation (1st operation) and further rehabilitation. Since then, the family took her to the place for treatment for several months in a year until the summer of 2009 when the treatment finished. The second operation was conducted 6 months ago.

The treatment and rehabilitation process for Hieu Nhi incurred many costs which were too much for her parents whose income is mainly from salary together with an additional income from extra work. Her mother works as filing clerk in a high school in the district while her father is a cycling coach of the province. During the treatment in Long Xuyen hospital (which is around 11 km from her house), the family spent around 40 to 50 thousands dong per day on travelling in addition to the costs for medicine, food, exercising tools (such as wheelchair, standing tool and splint, etc.) and toys. The treatment costs in Ho Chi Minh City were much higher. According to the estimate of her mother, every week, the family gave her and her grandmother (who stayed in the city to take care of her) approximately 1.5 – 2 million dongs. Such treatment was conducted for 3 – 6 months per year on average. Fortunately, their relatives sometimes gave them financial support so that the family could continue the treatment for her.

Barriers in the application for school

When she was 6 years old, Hieu Nhi could recognize the letters and communicate well (thanks to the teaching efforts of her mother and volunteers in the hospital in Ho Chi Minh City). With the hope for a future profession for their daughter, the parents were determined to apply for school for Hieu Nhi. At first, her mother registered her for the first grade of primary school. However, the registration was not accepted as she was too small to take care of herself and to go to the toilet on her own. The teachers there did not know how to take care of such children too. The mother then personally went to some centers for children with disability of the province. Again, she was not accepted as she was not either deaf or blind as well as not eligible for social protection. Those centers did not provide further explanation and advice on other places for her education. Powerless, the family had to send her to a nursery class managed by a friend of her mother. She was taught letters there. However, only after several months, as she was found not being able to go to the toilet on her own, her mother took her home to continue the treatment and rehabilitation process.

Up until August 1st which was also the date of meeting of the research team in An Giang province, Nhi's family again applied for 1st grade (at Primary School An Chau D). Once again, she was refused as she was too old for this grade. Despite of that, Nhi's mother still continues looking for the chances. She is now 12 years old.

Her capacity and the thirst for school

At the age of twelve, Hieu Nhi has not gone to school yet despite of the increasingly strong thirst for school. Mother still teaches her letters in the hope that she can learn a profession one day. According to her mother, Nhi already finished the curriculum of the first grade with mother as the teacher.

She now can read strip cartoon, write and do simple addition and subtraction. She communicates in a humorous and spontaneous manner and almost has no difficulties in expression and pronunciation. She can even make joke with adults and talk about her memories concisely.

She moves on her own with two clutches and walks on the flat ground. When going uphill, she needs the assistance of other people. She can have a wash and take care of herself. She can write and colour, read letters and text mobile messages (like "me oi con nho me" (Mom, I miss you) and "me oi co ba ut qua" (Mom, aunt Ut has just come to visit us). She can hold and do things as a normal person. She has good health and no other diseases. "Luckily, she has no diseases other than the disabilities" (shared his mother).

She is eagerly waiting for an opportunity for school. "I like going to school very much. I am about to go to school" – She shared with the research team.

Opportunity eventually came

The research team came while the family was thinking how to apply for Nhi's school. The team was accompanied by Mr. Nghia who is the expert of the Social Protection Division and also coordinator of the "Friendship" project in cooperation with UNICEF. After the talk, the team decided to assist her to go to school. Mr. Nghia promised to help the family during the application process and to influence the Department of Education and Training for her admission. The result was satisfactory. On our way back to Ho Chi Minh City (in the afternoon of August 4th), Mr. Nghia called and happily informed us that the Education and Training Division committed to finish, at any cost, the procedures for her school admission within the week (from August 2nd to 6th). Upon receiving the news, the research team members sighed with relief and were indescribably joyful. We are anxious to hear about his official admission into school.

Comments

Hieu Nhi is gradually recovering and will go to school after a long and hard time of aspiration. She herself and her family eventually feel satisfied to some extent. Various factors contribute to this success including the important roles of her family, of the child herself, of the communication and education system, the cooperation of different sectors, and the decision-making role of concerned authorities.

Followings are some considerations drawn from her case:

Nhi herself and her family is the prerequisite factor which directly leads to the success.
Hieu Nhi's family has made a lot of efforts and spent both human and financial resources for her treatment. Her mother and grandmother have alternately taken care of her in the past years during her treatment, back and forth, from Long Xuyen to Ho Chi Minh City. Many additional costs which are affordable only for families with high and stable income in An Giang province have arisen. I should think that if Hieu Nhi were born in another family which did not have either caretaker or such a large amount of money, no one knows how his condition would progress.

In addition, as Nhi's parents are both civil servants whose education and awareness level is higher than the general level, they can teach her when she does not have opportunity to go to school. The mother's efforts have at least contributed to establishing her language foundation before she goes to school. If Nhi belonged to another family whose parents have lower education level and are busy earning the living as same as many families in An Giang province, she might not have read, written and communicated by now.

Nhi herself has tried her best in physical exercises and kept learning. She makes friend with two forks, sets of strip cartoon and drawing brushes and hopes that she will go to school one day and perform as well as her peers. Luckily, this hope is also encouraged by her parents and grandmother. Therefore, Nhi always looks joyful and has no sign of sadness and complex like many other disabled children. This optimism has given her strength to move forward. Neighbours are source of spiritual encouragement while relatives give her both material and spiritual support.

Nhi's house is near the road. Children in the surrounding houses sometimes come to play with her. It is at least moment when she is cared by neighbours. Fortunately, "all neighbours love him and she respects them too… No one says or does something which makes her sad" (sad Nhi's mother).

Many of Nhi's relatives are civil servants. One of them is doctor. They occasionally send money to pay for the costs for her treatment in the hospital. Thanks to such assistance, Nhi's family can partly ease the financial burden for the treatment. Nhi's grandmother said: "Luckily, her relatives sometimes give money for her hospital treatment. Otherwise, we may not have money for the treatment".

Lack of a sufficient and practical advisory system from professional (trained) people sometimes results in the fact that Nhi cannot go to school in 6 years.

Nhi's mother has gone to schools and even schools for disabled children more than once to ask for Nhi's study opportunity. It is regretted that this mother did not receive any specific advice on such opportunities. She had to go home hopelessly after receiving answers like "She is not eligible for policy and not the right audience of the school"; "She is too small and not able to go to the toilet on her own; therefore, we cannot accept her"... It is supposed that instead of such short and irresponsible answers, these people explained further and introduced Nhi's mother to concerned authorities (like Training and Education Division and the Primary and Inclusive School Section), Hieu Nhi might not need to wait for 6 years for official school admission.

It is necessary to stress that although Nhi's parents are civil servants who have higher education level than most of people in An Giang province, they do not fully understand the rights for their daughter, at least the right for inclusive education and the policies to which she is entitled.

Therefore, an advisory system and inter-sector coordination is essential in community communication of different forms of education including inclusive education and exclusive education for disabled children as well as policies and regimes relating to disabled children.

Although Nhi's family is entitled to policy and regime late, it is better than never. In many cases, it is decisive to her school admission. During the past 12 hard years, Nhi's family has received only small financial assistance from local authority in the past two months. Before that, they received no material and spiritual support at all from local authorities. When the professional (child protection) people take part in the case, everything becomes much easier. This is proved by the fact that Mr. Nghia, the expert of social protection division, promised to influence the Department of Education and Training for Nhi's admission. As the result, Nhi was accepted for school within a week.

The involvement of concerned people is, therefore, very important and visits to households are very essential. If they cannot visit each household, there should be a system for detecting, reporting and strictly supervising of situation so as not to miss out any case like Nhi's one.

Annex 4: Rehabilitation in An Giang

Rehabilitation services in An Giang provincial hospital only met a small portion of CWD's demands. Specifically, the rehabilitation ward (in Long Xuyen general hospital) met only around 10 percent of CWD in need of rehabilitation in Long Xuyen city (according to the ward's rehabilitation doctor), let alone the entire province. The ward treated over 100 patients per day (they were mainly sent from clinical departments and partly from adjacent areas). However, the ward had only 3 rehabilitation officers working within an area of less than 20 m^2 large. This coverage was already overloading the hospital but far from meeting rehabilitative demands of the majority of CWD in the community.

District hospitals in An Giang were once equipped with some rehabilitation facilities and equipment, but these became useless due to the absence of rehabilitation professionals. According to doctor Hien, Head of Long Xuyen general hospital's orthopedics ward, “that is a waste”:

Many districts were supported with orthopedic facilities and tools. However, these have not been used whereas central hospitals at the provincial level needed these tools.

Regrettably, those facilities had been put unused in storage for years, and most of them became unusable. This reality was illustrated in the following quotation from an in-depth interview with a health care worker in Chau Phu district, An Giang:

“Although being provided with tools of physical therapy like horizontal bars, parallel bars, etc, in 1990s, there was no human resource and foundations for operation, we did not set up clinics and physical therapy wards. Now all of them got broken down”.

Annex 5: Rehabilitation in Dong Nai

Hospital-based rehabilitation services (Pediatric Hospital Number I) were well facilitated, however, there existed restriction in approaching the majority of CWD living in the community. Primary service recipients were post-operation CWD, those sent from clinical wards, or clients from adjacent areas for daily rehabilitation. Families with CWD in remote and distant areas, mostly suffered from hard economic conditions and could not come for daily treatment (day-boarding treatment).

One of the essential functions of the hospital-based rehabilitation center in Dong Nai was to offer training and transfer technologies to lower levels, but it was not effective in post-training supervision and technical support. Over the past 10 years, the center had opened many training/technical assistance courses for officers in charge of rehabilitation of commune health centers and village health workers/rehabilitation collaborators all over the province. Afterwards, officers in charge of rehabilitation in the community, however, worked almost independently and rarely got further technical assistance after training:

“I have been working in rehabilitation for 5 years so far, however, I have been trained only once. I have not got any chance to be trained again since then. There are only some movements (exercises) that I have been doing again and again, on the other hand, I can only give instructions for those families with kids who suffer from cerebral palsy and muscle stiffening mainly. I am not sure about other types of disabilities. (The person in charge of rehabilitation in Gia Canh commune)”.

“I had been trained in a village and mountain health care program, with rehabilitation exercises relevant for each type of disabilities like myasthenia, naughty kids, and kids with changes in behavior and awareness. Nevertheless, I was trained with those long ago (10 years). Since then, I have not got any further or intensive training… I mainly refer to books and newspapers, and work based on my living experience and some knowledge got from the handovers with the commune health center. (A village health care worker of Phu Vinh commune, Dong Nai)”.

Community-based rehabilitation program has been deployed since the year 2005 from provincial to communal levels, however, there have not had concrete assessments and amendments to fit the current context. The incentive regime for rehabilitation officers has remained modest, which means it is hard to get sustainability (at a modest level of 150,000 dongs per month). Most of the rehabilitation officers were health care collaborators (of hamlets and mountain villages) and they had been working mainly with their enthusiasm towards the society and CWD. However, their enthusiasm diminished as time went by. For instance, in Phu Vinh commune, 10 years ago, there were 4 village health care workers who got trained on rehabilitation, however, now only one of them continues doing the work:

“10 years ago, I got a support of 20,000 dongs per month, now 360,000 dongs (the total amount got from many programs, not only from the rehabilitation program). This amount of money is not much, I do the work as I have love for CWD. I get glad when seeing CWD abating well”.

Lack of technical support from rehabilitation officers was an issue in community-based rehabilitation in Dong Nai. In fact, rehabilitation officers mainly provided encouragements to CWD’s families through their home visits, but did not give technical assistance to them yet. For example, they visited families with CWD once a month, recorded in a monitoring book with CWD’s signals of abatement. However, they did not offer any concrete advice or suggestions in the book so that the families with CWD could follow. The above evidence was from the interviews and observations at two households with kids who suffered from cerebral palsy and had been joining in the rehabilitation in Long Binh ward, Bien Hoa.

The monitoring and supervision of the community-based rehabilitation services had been operating since the commencement, however, it did not emphasize technical assistance. The rehabilitation center of the Pediatric Hospital collaborated with the provincial health bureau to supervise rehabilitation personnel at commune and village levels once a year. District health department alone also paid 2-3 visits a year. Besides, rehabilitation officials at commune and village levels also attended monthly meetings at commune health centers. However, key contents of those monitoring events are reports of activities without any technical support or amendment on rehabilitation methods for CWD.

Families of CWD often did not collaborate with rehabilitation officers in following rehabilitation regimes for their kids. Only parents who were well aware of the importance of rehabilitation and who possessed sufficient and favorable conditions (e.g., time, money and baby-sitters), would easily collaborate with rehabilitation officers. Otherwise, most families often gave up as they paid more attention to their livelihood, switched their cares to other kids or lost their hearts as they did not see their disabled kids making progress.

Rehabilitation facilities at households and commune health centers remained rudimental. Rehabilitation tools were mainly created by the households. Common tools included sticks for toddling, bamboo sticks, and pulleys for pulling to assist CWD to learn how to do walk and stand up. Other types of tools, as simple as hand-used balls, were not available and even unaffordable to many households. “While most of families with severely disabled kids here had to strive for their daily livelihood, such balls seem luxurious to them. (According to the head of Gia Canh commune health center)”.

So far, some successful rehabilitation models existed but have not been recognized and popularized yet. For instance, in Gia Canh commune, according to the head of the commune health center, families became more and more favorable and supportive of the community-based rehabilitation program. At first, the implementation encountered several difficulties. CWD’s families almost did not collaborate with the staff. Years later, however, the work got easier because in reality, there were CWD who could walk by themselves after a year of practices. Such successful cases should be thoroughly analyzed and regarded as good samples to be widely popularized in the community with CWD.

Annex 6: Key findings on CWD data base

Themes	Key findings
Classification of CWD based on social functions	CWD in two provinces are classified into four key groups: the group that is nurtured at social protection centers (beneficiaries of social welfares and helpless folks); the group that is learning at exclusive schools for CWD (hearing-impaired children, visually-impaired children, and partly the children with mental impairment - retardation); the group of inclusive education (learning with non-disabled children); and the group that lives in the community (heavily impaired children that have never gone to school or have ever left schools). Both provinces have social protection centers and exclusive schools, and deployed inclusive education programs for years. Most of CWD living in the community, however, have not approached those above-mentioned institutions.
Supervision and reporting system on CWD	Inter-coordination among education, health care, social protection sectors has not been really formed, if yes, it just stops at the level of concrete activities, but has not become systematic yet. These sectors have operated almost independently among one another in CWD-related aspects. Identifying, reporting and supervising system on CWD has neither been standardized in data collection techniques, nor been consistent among the three sectors of social protection, education and health care, which led to different statistics of CWD in each sector. This largely affects the assurance of incentives and opportunities to approach CWD-related services, including education, health care, rehabilitation, and employment.

Annex 7: Key findings for knowledge on disabilities in children

Themes	Key findings
Definition and classification	Knowledge on definition and CWD classification among study groups is inhomogeneous, incomprehensive and reflects real experience or imagination on CWD. The kids themselves often give out examples of one CWD that they know from reality, television, radios, papers, and even their imagination. The examples are often limited into one or two types of disabilities (mainly mobility and intellectual impairment). The children often failed to point out reasons for disabilities while tending to classify disabilities into "normal – walkable" and "abnormal – unwalkable". The adults in this research are more aware of and comprehensive about definition and classification of disabilities. For them, disabilities are not simply physical deficiencies but also means spiritual wounds and economic pressures for their families. They can easily classify disabilities based on types, causes, and severity of the disabilities.
Causes of disabilities	Awareness on causes of disabilities is incomprehensive, imprecise with remarkable differentiations between the children and adult groups and between the two researched provinces. Children do not often care about nor try to explain causes to disabilities while adults put forward numerous causes. Nevertheless, the causes are not consistent between the two researched provinces: in An Giang community attitude holds that "disabilities mean maltreatment by the god" and in Dong Nai that "disabilities are caused by dioxin". These perceptions sometimes overshadow other important reasons which need public health attention. Remarkably, parent groups with severe CWD in An Giang are often vague about causes to disabilities; they do not try to learn why their children suffer from disabilities.
Prevention of disabilities	Knowledge on prevention of disabilities among parent groups with CWD, even among those parents with non-disabled children is very limited. Most of the interviewees in this research neither actively prevented against disabilities or nor learned any preventive skill or measures at all.
Early detection and treatment	Early detection of disabilities depends much on types of disabilities. Physical impairments (legs, hand, eyes, lips and mouth, etc.,) are often easily detected right after the deliveries or during the first 2-6 months afterwards. However, with intellectual impairments (Down syndrome or mental retardation), behavioral disorders, and particularly cerebral palsy, the detection of the impairment is often hidden behind a pernicious disease. Normally, it is late at the time, which commonly shall require more efforts to bring up and have the children rehabilitated. Early treatment for disabilities is a problem for two study districts (Dinh Quan in Dong Nai and Chau Phu in An Giang): either to wait until the disabilities get more severe or to have early but careless treatment based on experience.

Annex 8: Key findings for health care and rehabilitation

Themes	Key findings
Actual state of health care and rehabilitation	**Medical examination and treatment** CWD's parents did not often take initiatives to take their kids out for periodical medical examinations but only did so when their kids' disabilities get severe. It was common for parents to take their kids out for medical examinations and treatment at private facilities or buy medicines to treat their kids themselves. Kids in exclusive schools and in state-run social protection centers particularly got free-of-charge medical examinations and treatment through associated health care programs among those units, provincial hospitals and health care services. **Rehabilitation** Parents often found ways to rehabilitate their kids by themselves (based on their own experience), or even if being instructed, they showed impatience in maintaining practice regime and tended to withdraw when their kids' disabilities did not get improved. **Home-care and hygiene** While the majority of CWD (especially the severely disabled group of mobility, behavioral disorders and intellectual impairment) was not given with full and sufficient health care, they were more attentively cared of home-care and hygiene. **Good, typical example of health care and rehabilitation** Few families, often those households with good economic conditions and wealth, cared much for their disabled kids and strictly rehabilitate them. Kids in those families often made progresses, not only in terms of physical health but also spiritual health and intellectual development. Such success was resulted from favorable determinants: economic capacity; presence of people who provided regular and attentive care for CWD and had knowledge and experience on kids' diseases; and particularly having constant relations with health care centers or experienced doctors.
Influential factors	**CWD themselves and their families:** CWD were prone to diseases, however, their parents lacked knowledge on disease prevention for them so they were often passive in preventing against the diseases and giving treatment for the kids. The parents' knowledge and skills to rehabilitate the kids remained limited, especially those in An Giang: they either did nothing or rehabilitated the kids based on their experience or gave up as they found the problem not improved. The parents often lacked belief in their kids' progresses so they lost their heart to maintain practice regime for their kids. Far distance from home to health care centers was another big barrier for CWD to get medical examinations and treatment. Poverty and hard work were the top leading reasons to the parents' unwillingness to take CWD out for timely medical examinations and treatment or periodical medical check-ups.

Themes	Key findings
	Health care and rehabilitation system ***Health care system*** High technologies of early diagnoses for disabilities and rehabilitation were now available at big hospitals only, meeting little demand of CWD's at communities. Both provinces had not made any remarkable effort to boost up the community's knowledge on causes, types, preventive measures, and early intervention of disabilities. Absence of an effective health care consultancy system on disabilities in CWD with indifferent attitudes of public health care workers widened the gap between CWD's parents and public health care units. On the contrary, there were examples of doctors who were whole-hearted and devoted to help CWD's families, however, it was not common in the study sites. Health care collaborators had been operating for years, but their work remained ineffective due to their sparse working areas, cumbersome tasks, their lack of professional knowledge and skills, and modest incentives. ***Rehabilitation*** The current rehabilitation system, both at hospitals (in both provinces) and in the community (Dong Nai), mainly focused on mobility disabilities, and fails to meet CWD's real demands. The key problem of An Giang now included the shortage of infrastructure, equipment, and human resource for the hospital-based rehabilitation system whereas the entire work of rehabilitation at the district level and in the community had been left untouched. In Dong Nai, while the hospital-based rehabilitation served a small group of CWD of mobility, the community-based rehabilitation confronted various challenges: lack of facilities; wastes of resources (trained rehabilitation staff did not performed their expected tasks); CWD's families were impatient and uncooperative with staff; lack of technical supervision and assistance for grassroots level; and lack of incentives for staff/collaborators. **The policy** Health care policies of free-of-charge medical examinations and treatment for kids under 6 years old and for severe CWD over 6 year-old born to poor households was under implementation in the two provinces, however, it was not actually just for all beneficiaries. Local authorities did not work out optimal measures for residents, especially households with CWD, to know about policies and how to claim for their interests when injustice occurred.

Annex 9: Key findings for education for CWD

Themes	Key findings
Motivations and obstacles from CWD and their families	**Parents' attitudes toward CWD's learning** Parents were generally supportive of their kids' learning, but often hesitant and concerned in selecting among different education types for their kids. As for kids with severe intellectual retardation, cerebral palsy, and behavioral disorders, their parents were quite discreet and worried because their kids did not have ability to care for themselves; they were concerned that teachers would not have much time to care for their kids as they had to care for non-disabled children; worried that their kids would be bullied by friends of same age; they did not earn enough money to cover school fees (as the majority of them were very poor). Parents of kids with minor impairments which still allow CWD to participate in casual activities with non-disabled children were not worried about their kids' learning at inclusive schools. Many parents, especially those with severely disabled kids, wished that their kids could learn at specialized schools, believing that their kids would not be bullied by normal kids and would be cared for more attentively there. **Barriers from family perspective** Despite parents' support of their kids' going to school, the severity of the disabilities and unexpected health conditions of CWD; far distance from home to school; poverty and parents' losses of potential employment opportunities if they spent time bringing their kids to school ; perceived hardship for the CWD at school; unawareness of education opportunities and benefits for CWD; and lack of belief in the children's ability to learn were major barriers preventing many CWD from continuing their school to undertake domestic chores.
Inclusive education	Most of CWD at inclusive schools had mobility impairment or disabilities. Children with other types of disabilities such as hearing impairment, visual impairment, behavioral disorders and intellectual impairment were few in this type of education. The quality of inclusive education was limited because: teachers not well trained and given with adequate technical assistance for inclusive teaching; lack of CWD-friendly, supportive and rehabilitation facilities at school settings; lack of documents and quality assessment system for CWD; lack of entertainment activities, especially physical education for CWD; modest incentives for inclusive school teachers; and absence of a successful model of inclusive education.
Social protection center	The number of social protection centers was limited and partly met demands of kids with severe disabilities in the list of beneficiaries of social welfares (20 centers in Dong Nai nurturing over 3,000 CWD and only one social protection center in An Giang with around 20 CWD). Social protection centers mainly focused on nurturing activities, but less on provision of knowledge, vocations and living skills for CWD.

Themes	Key findings
	General difficulties at those centers lied in lack of material facilities, teaching and rehabilitation equipment for CWD, especially lack of caring skills for personnel. CWD at social protection centers often lacked opportunities for exchanges and integration into the outside communities.
Exclusive education	Exclusive schools at present were few in number, thus accommodating a small portion of CWD in need. CWD here mainly suffered from hearing impairment, visual impairment and some kids with intellectual impairment. These schools are well facilitated with equipment for learning, rehabilitation, entertainment and vocational teaching. Challenges included an absence of standardized assessing placement, syllabus; teachers' lack of skills to deal with different types of disabilities and diseases; lack of teaching manual and materials; lack of supportive supervision mechanism from higher levels; lack of opportunities for CWD to really integrate into the community; restrictions in vocational guidance, vocational training and employment opportunities after graduation; absence of an effective and intensive counseling system of early intervention and education opportunities for CWD and their families in the community (although counseling services on early intervention were available at school but on a restricted scale).
Education in the community	CWD groups in the community almost did not have any chance to approach education. As for CWD who were about to enter elementary school, their parents and baby-sitters would play a role as key instructors, however, this depended on the parents' levels of education and the baby-sitters' willingness and devotion. Those CWD who did leave school almost lost chances for further studies. None of CWD who left school wanted to continue learning in a general education system. Only few of them wished to learn a vocation and go to work for money afterward. As for severe disabled group, family was the only place of care and education. Besides some social protection centers (they were not located in the two researched districts), no form of community education and care existed for this group of CWD.
Obstacles from community and policies	There was an absence of efficient surveying and education counseling system for CWD; lack of collaboration among authorities, sectors, and unions on mobilizing CWD to go to school; lack of a supportive and policy consulting regime for CWD; the community's acceptance of CWD's working; and the people's passiveness to claim for interests for CWD. All these remained as burning challenges at the community level in promotion of education for CWD in the two provinces.

Annex 10: Key findings for access to information

Themes	Key findings
Habit of information acquirement	Parents of CWD do not often take initiatives to seek information related to their kids, but passively acquire information from such other people as health care workers, teachers, especially personnel at grassroots level like the hamlet's head, women union, health care workers, and collaborators/ volunteers.
Information channels	**Information channels for parents** The main information sharing system in the community (for parents) in the two study provinces operates through commune/hamlet personnel like population collaborators, hamlet health workers, women union members, and word-of-mouth patterns among the community's members. These communication patterns become the most popular and preferred channel for parents for their popularity and commonality. TV and loudspeakers are common at grassroots level, but accessibility to these media is limited because local residents mainly work on farms far away from home. Moreover, the information's contents on CWD delivered through these media remains poor. Other means of communications like brochures, leaflets, posters, road march … on CWD have never been used in the study areas. Occasionally, some communes publicly celebrate CWD's learning achievements through which local people had a chance to learn about CWD. The consulting system on disabilities and CWD-related rights has not been effective in both provinces and stays hollow. Personnel in charge, especially health care workers, do not get enough information on services for CWD and they seriously lack counseling skills. **Information channel for CWD** T.V and radio are the two main channels of information for CWD in the community. They like watching amusement programs like sports, music and game shows the most. Few of them also read books, papers or cartoons brought home by their parents. Kids at inclusive schools also received information from their teachers, friends, libraries (books, papers, tapes and disks) and T.V, radio. Some of them can use Internet. Kid groups at exclusive schools, besides the key source of information from their teachers, they can also access Internet (with sound-devised software for visually impaired kids); documents and newspapers in Braille embossed letters; books and newspapers; video and audio disks; and television channels. Some programs and television channels utilize "notation or sign language" to increase accessibility to those people with hearing impairment (e.g., HTV7 and O2 TV). Regrettably, few kids can access the above-mentioned

Themes	Key findings
	two channels. Moreover, “the notation language” used in the two channels is hard for CWD and teachers in the two provinces to understand because it has not been standardized nationwide.
Communication quality	The quality of communication at the community level is low due to the lack of communication skills and post-communication supporting mechanism. The key communication method remains one-direction with little or no visual illustration or interaction between communicators and audience. Health care and education facilities were short of information and counseling skills and thus disappointing parents in need. While communication quality is low within the community, the very diversification of information channels and regular interaction between CWD and their teachers, friends at schools impregnate them with important values for life such as equal treatment, self-respect, and endeavor. Lessons of civics at inclusive classes; protection and privileges provided by the teachers; and especially examples of CWD who overcame difficulties to get successful at learning, even brilliant at work through T.V, radio, newspapers and in life served as a useful catalyst to help them build up the above values.

Annex 11: Key findings for public and entertainment services

Themes	Key findings
Entertainment activities	Most of CWD take part in many folk games with a lot of exercises - whether at home, in the community or at schools - spontaneously without adults' instructions and protection. Unfortunately, those kids with severe mobility disabilities (like leg crippled) or behavioral disorders (epilepsy or mobility disorders) rarely have chances to join in such activities. Besides folk games, local communities or inclusive schools did not have other amusement, recreational, physical training activities appropriate for kids' disabilities types, especially with the group with severe disabilities and intellectual impairment. Exclusive schools show more dominant in creating appropriate playing environments for CWD of different disabilities, however, they do not create enough inclusive opportunities in outside environments. Recreational activities at social protection centers remain very poor, mainly focusing on nurturing CWD but not caring about recreational activities for them. Bien Hoa nurturing School for CWD and orphans is an exception with recreational and amusement areas, friendly classes, rehabilitation and vocational activities relevant to disabilities types and the kids' hobbies. However, even this center does not provide enough opportunities for CWD to integrate into the mainstream community. Besides the games and exchange sessions, CWD often watch television (particularly films and game shows), read newspapers, listen to radio or do things that they like on their own such as drawing, collage… This pattern is similar to all types of disabilities (if they were able to do so) and in all contexts.
Public services	Architectural works, transport system, parks, public toilets, and amusement parks in the two provinces almost do not care about disabled people's demands. In An Giang, there is only one park in Long Xuyen center that is facilitated with a separate path in the toilet area for disabled people and the provincial school for CWD is facilitated with corridors designed for visually impaired CWD (they are paved with coarse tiles in the middle of the path). There are buses in Dong Nai that provide free-of-charge services to CWD but they must have commutation tickets (bought for them by the provincial exclusive school).

Annex 12: Key findings for vocational training and employment

Themes	Key findings
The network of vocational guidance, training and employment opportunities	Vocational training for CWD in both provinces encounters several difficulties involving recruitment, vocational training process, and searches for employment opportunities for CWD. The number of vocational training facilities stays very limited. There are 4 vocational centers in Dong Nai, but there is not any in An Giang so it has to collaborate with some vocational training facility to provide the service. Almost all vocational training centers do not have teachers in charge of CWD, which limits technical transfer to the kids. Creating job opportunities for kids after the training confront various challenges and instable, largely due to the inconsistency in recruiters' demands and CWD's abilities. Influential factors on an employment opportunity for CWD include the opportunity's moment; CWD's intellectual levels and health conditions; technical requirements; and the distance from their homes to working place. The two provinces have experienced some successful models of vocational training and employment creation for CWD. Dong Nai has two models: Long Thanh garment facility – that accepts almost 100 CWD. It provides accommodations for the kids; and the Association of disabled people who better themselves in Xuan Loc (20 members)– set up and managed by a man with disabilities in the leg. The association specializes in repairing household appliances and computers and utilized repairing fees to maintain its operation, feed the members and give vocational training for other members. An Giang possesses an associated model between the provincial school for CWD and Kim Chi garment facility in Long Xuyen, however, there has not got any long-term orientation for development.
Barriers and motivations arising from families	Poverty, parents' feeling sorry for their kids and the kids' health conditions remain barriers for CWD's vocational training. Without ties of poverty, families tend to motivate their CWD to attend vocational training and to find jobs. They often take initiatives to give vocational guidance or motivate their kids to go learning. However, in this study, few parents had such experiences and they were often wealthy cadres.

Annex 13: Key findings for values and life skills

Themes	Key findings
Opinion on friendship	Friendship is spiritually important for CWD either at school or at the residential area. Most of CWD in this study (except for those with severe disabilities and a complex) fondle friendship and feel happy when having chances to live in friendship. When they are not welcomed or allowed to play with by their friends, CWD often isolate themselves within their own world, getting lonely or look at other kids playing with a thirst for a friendship.
Opinion on family	For most of CWD, family is a love nest and the place where they find more comfort and safety than in any other place. In their minds, family is placed in the close relations with neighbors, close friends nearby, even with pets that they are fond of, but not simply related to their parents or siblings. For them, loves and cares of relatives, especially parents and siblings, play vital roles in nurturing their spiritual health. They will feel empty and sometimes hold their parents and siblings responsible as their parents and siblings do not spend adequate time playing with them (particularly the severe disabled group).
Opinion on school	CWD in this study do not have any special impression on their schools, but the friendship at schools and team games. Noticeably, while many pupils at inclusive schools admit that the teachers treat them well but they did not seem to love teachers. This may be attributable to the fact that teachers commonly give “naughty kids” penalties like scolds, even beats (both disabled and non-disabled kids) in stead of employing more friendly rewarding measures. Teachers’ attention, friendliness, and empathy are the most powerful catalysts to draw CWD closer to the teachers.
Opinion on neighbors	Relations with neighbors are very important for CWD, serving as a stable playground and a string to connect them with the community, especially when the neighbors have kids of the same age with them. “Neighbors’ kids” play a decisive role in connecting CWD with adult neighbors thanks to those relations. Interactions among the neighbors make CWD always feel that they are understood, sympathized, and protected. Regrettably, CWD in urban areas do not always have such a friendly neighborhood because their “neighbors” are often away home for work.
CWD’s life skills	In general, CWD lack communication skills, especially in disclosing their demands and emotional feelings to others. They tend to suppress their feelings about troubles and unfairness caused to them by other people. While most of CWD tend to do so, some of them employed delicate behaviors, which not only helps them to avoid sneers and bullies but also helps strengthen their existing relations and friendships. Some successful

Themes	Key findings
	behaviors are: “giving gifts to their friends instead of getting sulky with them”, or “take initiatives to express their expectations and uneasiness so that their friends will get sympathetic and support them”, always be cheerful and respectful for their friends.
Motivations for CWD to better themselves	Images or stories about disabled people (especially examples of success) in real life, on T.V or newspapers, magazines, books, notebooks, even on Internet, are often interesting for CWD and give them more strength to get through life endeavors and crisis: at least they will get willing to ignore discrimination and make efforts to better themselves.
CWD’s aspirations	Two main dreams of CWD prevail in this study: wish to continue learning so as to get a relevant job; and wish for the disease not to get worse. CWD in An Giang are more open-minded to share their dreams than those in Dong Nai and often wish to get a job rather than wish for better health conditions. Most of CWD in Dong Nai, even the learning group, are very reserved to express their aspirations and often wish their diseases not to get more severe. Their aspirations are seldom related to job opportunities or career development.

Annex 14: Key findings for family and social attitudes and roles

Themes	Key findings
Families' attitudes in caring for CWD	Although being considered as family's burden with any type of disabilities, CWD are still pampered and loved by their parents. Most of them are cared for with parents' loves. In general, parents tend to accept their disabled kids as less advantageous family members, thus often reserving more sentiments and cares for them compared to other kids in the family. In wealthy families with people continently available at home, CWD are cared more attentively than those in poor families with few members. Parents and grandma are the main care-takers for CWD. They are sources of great encouragement and foundations to create feelings of safety for CWD. However, few CWD do not get protection, supports, and empathy from their parents so they always feel missing and seek for escape from their families. Other relatives like uncles, aunts, and siblings undertake a small part in caring CWD. Siblings mainly spend time playing with CWD while other members can support the parents to take CWD to school, and to medical check-ups. In some rare cases, relatives provide some financial aid, or feed the kids.
Attitudes at schools	**Teachers** In general, teachers at inclusive schools are much interested in teaching CWD (spending more time preparing for lessons and giving instructions) and protecting CWD's interests (through lessons of civics and correcting non-disabled kids' misbehaviors towards CWD). Schools' leaders also support CWD by creating all possible opportunities for them to learn, and to sit for tests, examinations, and encouraging them to continue learning (dispatching gifts to CWD, encouraging parents to bring CWD to schools through home visits, offering exemption of and reduction in school fees for poor CWD, celebrating events to recognize CWD that overcome difficulties…). Nevertheless, schools' leaders and teachers have not created a close and interactive relation between the schools and families in a common cause of education and care for CWD. **Non-disabled kids** In general, non-disabled kids feel sorry for and support CWD in learning and life. There are three popular patterns of help that non-disabled kids give to CWD: 1) Supports in learning; 2) Supports in games like carrying CWD when they run, feeling tired, or accepting CWD to play with them although CWD can not play well; 3) Supports in cases of being bullied.

Themes	Key findings
	Concrete stories about mutual affection and love between non-disabled kids and CWD commonly occur within close networks or friendships (close friends). There still remain phenomena of discrimination and maltreatment among non-disabled kids toward CWD, especially with visually and intellectually impaired groups. These phenomena, however, disappear shortly without repetition if timely intervened by the schools' teachers. Otherwise, the problems persist to deepen CWD's pains and beyond CWD's resistance.
The community's attitudes	**Affection and support** Affection and spiritual support form the main attitude within communities in which CWD study and live. In many cases this attitude is transformed into material support or protective actions for CWD. Teachers, friends, and neighbors are the closest people and have most opportunity to share with CWD. **Discrimination and self-discrimination** Obviously or wittingly, discrimination still exists around CWD and their family under many forms (speech, eye contact, avoidance or bullying actions), and sometimes creates long-term stress or psychological effects for CWD. These kinds of discrimination appear in all contexts and classes, however they are more popular among groups of children (between CWD and non-disabled kids) because they usually learn and play with each other more than with adults. Many discriminations lead to "self-discrimination" and the later form of discrimination is often more serious because it tends to isolate CWD from the outside environment. Unfortunately, those signs of discrimination and self-discrimination are not seen as critical issues in the eyes of adults: teachers, parents, community's leaders and staff of authorized sectors and unions. They all have the tendency to think that nowadays, the society have known much more about the disabilities and therefore they have a sympathetic and supportive attitude instead of discriminating CWD. Unfortunately, that statement is, in fact, a dangerous subjective viewpoint which unduely justifies for the lack of their care for psychological problems of CWD. **Fear and avoidance** Fear and avoidance are a special form of discrimination in this research, and the most affected groups were intellectually impaired children (especially Down syndrome) or children with behavioral disorders. The reason is that they are afraid of being put in danger caused by these children's behavioral disorders.

Themes	**Key findings**
Local authorities' attitudes	Support from local authorities, unions and staff (at commune and village levels) is very important to ensure the rights of CWD and to partly assist their family with material when they are in difficulty. However it is still unsystematic, unfair and unpopular for all communes. The three common forms of support from the local authority are: 1) organizing visits and giving presents to CWD; 2) calling for donation for families with CWD and especially those with difficult situations; 3) implementing the policy and law for CWD. These three forms are meaningful to CWD and their families. Regretably, the implementation of such support is not synchronous nor systematic, and therefore leaving many CWD who should have been received benefits unsupported. Firstly, most of the communes organize visits and giving presents for CWD and their family but not regularly and just in formalism. Secondly, most of these communes have donation programs but these programs are very restricted in scale and beneficiaries, while not really focusing on systematic activities so that all CWD in the community can benefit. Thirdly, although local authorities have implemented the laws for children and relating decrees such as Decree 67 (which now becomes Decree 13) in the recent years, they still leave some beneficial children untouched due to inadequacy in surveying, listing, supervising, and supporting CWD.
Roles of mass organizations and relevant agencies	Nowadays, activities related to CWD at the grassroots level are integrated within the overall child-caring and protecting activities, and the sectors and unions take part in implementing the rights of CWD mostly act independently, but not under an overall coordination. The three main sectors directly implementing the rights of CWD include education, health care, and social protection. However these sectors mostly act individually. It's hard to see the relation in functions among these three sectors from investigating, identifying and classifying CWD to implementing the rights for them. Women union, youth union, and Red Cross largely take part in communication and public awareness raising campaigns, calling for actions and organizing cultural, social and inclusive activities. But these agencies have not had a common mechanism in collaboration and task-assignment for all and each sector in implementing the rights of CWD. Besides these above main sectors, each commune has a network of collaborators serving multiple roles and having high potential of self-coordinating among their different kinds of activities. However, they do not have a clear-cut responsibility assignment and collaborative mechanism, but working under task-based assignments.

Annex 15: List of IEC materials

Categories	No	Title in English	Organization/ Author	Publishing house	Publishing year	Form	Contents	Targeted audience
Intel NGO and Vietnamese social organizations' Brochures & leaflets: General Introduction of activities, including assistance for PWD	1	2007 Annual Report	East meets West Foundation		2007	Report	Review EMW activities in 2007	This document is for those who care for disabled people
	2	Reach Viet Nam	East Meets West Foundation		2008	Magazine	Review of EMW activities for 20 years in Viet Nam	
	3	Fed Hollows Foundation Viet Nam	Fed Hollows Foundation Viet Nam			Brochure	Introduction of Fred Hollows Foundation and its main working area of saving rights in Viet Nam.	
Rules and Guidelines	4	Guidelines for managing and implementing early intervention for CWD of pre – school level.	Ministry of Education and Training, Department of Preschool Education		2007	Book	Define and process of early intervention for CWD, instructions to implement early intervention	This document is for the community
	5	Convention on the Rights of People with Disabilities	National Coordination Committee on Disability of Viet Nam		2008	Book	Rights of people with disabilities	This document is for the community
	6	Rights of children with disability in Viet Nam	Unicef		2009	Report	Children with disabilities and their rights in Viet Nam	Relevant agencies to disabled people

Categories	No	Title in English	Organization/ Author	Publishing house	Publishing year	Form	Contents	Targeted audience
	7	Guideline about community development method focuses on children.	Plan		2004	Book	Provide useful information about community development focus on children	For Plan's partners
Books/ Brochure/ Magazine on Disabilities	8	Inclusive education for deaf children (parents guide skills)	Medical Committee Netherlands – Viet Nam		2004	Book	Training materials for parents of deaf children: the knowledge needed to understand the situation of children and the skills needed to encourage and promote communication in children.	Parents of children with disability
	9	Inclusive education for deaf children in the context of Viet Nam	Medical Committee Netherlands – Viet Nam		2003	Book	Training materials: hearing problems and methods to strengthen communication in deaf children in the community	Teacher of deaf children
	10	Inclusive education for deaf children (materials for parents)	Medical Committee Netherlands – Viet Nam		2004	Book	Training materials for parents of deaf children: guide parents to help children integrate into the community	Parents of children with disability
	11	Results of some qualitative research on disability	Medical Committee Netherlands - Viet Nam	Medical Publishing House	2008	Report	Results of case studies on issues of disable people such as: vocational education for disabled people, the need of preventing to accidents for blind children, the difficulties of students with disabilities in Hanoi	Relevant agencies to disabled people

Categories	No	Title in English	Organization/ Author	Publishing house	Publishing year	Form	Contents	Targeted audience
	12	Decade of disabled people in Asia – Pacific region, 2003 – 2012.	Economic - Social Committee Asia - Pacific	Labor and Society Publishing House	2005	Book	The common problems of people with disabilities in Asia - Pacific region and the community work to improve the lives of disabled people	Relevant agencies to disabled people
	13	Rehabilitation base on community.		Medical Publishing House	2006	Book	Situation of people with disabilities and their families in Viet Nam, their rights and rehabilitation base on community	Material for people with disabilities and their families
	14	Report on children with disabilities and their families in Da Nang (Knowledge - attitude – behavior)	TNS, Unicef		2009	Report	The common problems of children with disabilities and their families in Da Nang, the attitudes of society and what society should do to improve the lives of children with disabilities	Relevant agencies to disabled people
	15	Manuals in inclusive education for disabled pupils	Le Tien Thanh – Tran Dinh Thuan – Nguyen Xuan Hai	Viet Nam Education Publishing House	2009	Book	Types of disabilities and educational methods to help integrate children with disabilities	Materials for primary school teachers
	16	What should we do to help children with disabilities	Ministry of Education and Training, Department of Preschool Education			Leaflet	Pointed out what society should do to help children with disabilities	This document is for the community

Categories	No	Title in English	Organization/ Author	Publishing house	Publishing year	Form	Contents	Targeted audience
	17	Early intervention and inclusive education for children with intellectual disabilities	Ministry of Education and Training, Department of Preschool Education			Leaflet	Show identification of children with intellectual disabilities and what should be done to help them	This document is for the community
	18	Early intervention and inclusive education for blind children	Ministry of Education and Training, Department of Preschool Education			Leaflet	Point out the causes and identification of blind children and what should be done to help them	This document is for the community

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