

Research Report on Children with Disabilities and their families in Da Nang

Knowledge - Attitudes - Practices

Report for



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The list of agencies and personnel interviewed can be found in the Appendix of this document.

EXECUTIVE SUMMARY

It is estimated that there are over 1 million children with disabilities (CWD) in Viet Nam. Similar to the movement globally, Viet Nam is shifting towards a social model of disability to facilitate inclusion of this segment in to society. This model has its focus on required changes in society in terms of attitudes, social support, information and physical structures that will enable the potential of disabled people to contribute to society and add economic value.

UNICEF Viet Nam commenced a cross sectoral program for CWD, including Victims of Agent Orange, in 2008. This program builds on existing UNICEF-supported work and partnerships to strengthen policies, legislation and programs for CWD and their families. It includes both national and sub-national components. At the sub-national level, the project focuses on capacity development, advocacy, service delivery and research. Da Nang in central Viet Nam has been chosen as the first of a proposed three sites for this project.

Research was required to understand capacity gaps and to inform policy development, as well as to inform communications development that can change both individual and social behaviour. The purpose of this research study is thus threefold: firstly, to understand the knowledge, attitudes and practices of CWD and their families; secondly, to understand the perceptions of the community towards CWD and thirdly, to understand the role of stakeholders (key governmental and non-governmental) in this area.

A two-phase research design was necessary to meet the information needs. The first phase - a quantitative phase constituting a community survey to measure the perceptions and KAP of the community of Da Nang towards the CWD and their families was designed. Face to face interviews were conducted amongst the general population, aged 18-69 years across the 7 districts of Da Nang: Hai Chau, Thanh Khe, Son Tra, Ngu Hanh Son, Lien Chieu, Cam Le and Hoa Vang. The sample size was n= 150 and quotas were applied by gender and district.

The second stage –was a qualitative phase with CWD, parents of CWD, children without disability and relevant stakeholders. The key objective of this component was to understand in-situ, and in detail, the issues for CWD and their families. The children without disability component helped to augment community understanding of facilitators and barriers to social inclusion of CWD. The stakeholder component addressed understanding the stakeholder perspective, what is currently being done, and perceived priorities across the government and non-government network. This phase was composed of two sections: ethnography with CWD and their families and focus groups with Parents of CWD, as well as one focus group with children without disability. Building on the findings of past studies, an ethnographic approach to studying the issues of CWD's and their families was taken rather than relying solely on a focus group discussion methodology. This helped to mitigate some of the issues found in past studies which found difficulties for CWD opening up an a focus group environment; likewise the researchers were limited in their ability to use non-direct methods, such as observation, which help to understand the issues better in an 'in-situ' environment. The second section was indepth interviews with a mix of relevant stakeholders and collection of available IEC materials.

The main study findings are presented in 3 parts. The first part addresses the knowledge, attitudes and perceptions of the families and their CWD, and where relevant, also presents both the social perspective of the community and the stakeholder perspective on the key issues. The intention is to allow the reader a holistic and integrated view of the findings. The second part looks at the issues explored around current systems and support towards integration and inclusion of CWD in society. Again, the view of the

different stakeholders is provided. The final and third section looks at the communications objectives of the study, primarily who to target and prioritize with communication, what the key messages should be, and the means through which to communicate them. Advanced statistical analysis, in the form of cluster analysis was used to support this objective.

In conclusion, it is noted that **whilst there is a lot to be done, there are positive bases for change**. It is also noted that we see consistency in the knowledge, attitudes and perceptions, across the individual, family, social and stakeholder levels, **thus targeted efforts should leverage change across the board**.

At a social agency level, **better coordination is essential** to ensure the efforts of all stakeholder groups are synchronized towards clear and effective outcomes. **Better information**, in the form of detailed statistics on the CWD population will strongly support this. **Financial support plans for families are necessary** and already in planning as a priority with consistent and easy access to support critical.

With regards to healthcare, **better education around healthcare** for CWD and their families, as well as healthcare practitioners is essential. **Improved facilities and equipment** in hospitals, as well as an increased knowledge on rehabilitation is also required.

Inclusive education issues need to be addressed through awareness raising around inclusive education itself for CWD and their families, as well as education for teachers/education practitioners. Developing support materials and programs by type of disability, age and general motivation to teachers are key supporting factors. Where inclusive education exists, there is positive response on all levels, yet the perceptual barriers are also high across the board.

When it comes to **infrastructure, policies need to be developed** in relation to public construction and accessibility for PWD and CWD, **especially in relation to transportation and the accessibility of schools**. A strategic matrix seeks to summarize the key improvement factors necessary across the different areas.

The **positive perceptions of families and the community are key to trigger** in a broad and significant communications strategy to help drive change and impact knowledge, attitudes and perceptions at an individual and community level. **The majority of the population demonstrates perceptions and beliefs that can be targeted to generate significant shift towards a social inclusion model**. TV and Print are the mainstream means of communication to target, whilst a better strategy around information materials across both urban and rural areas is also indicated as an obvious communications need.

INTRODUCTION

Introduction to the study

UNICEF Viet Nam submitted a project proposal to the Ford Foundation for a cross sectoral program (health care, education, water and sanitation, child protection and social inclusion) for Children with Disabilities (CWD) including Victims of Agent Orange in Viet Nam. This program commenced in 2008, building on existing UNICEF-supported work and partnerships to strengthen policies, legislation and programs for CWD and their families. This program includes both national and sub-national components. At the national level, the focus is on policy and legal framework. At the sub-national level, the project focuses on capacity development, advocacy, service delivery and research. Da Nang in central Viet Nam has been chosen as the first of a proposed three sites for this project.

To implement the program, UNICEF adopted a multi-sectoral, rights based approach and is guided by both the Convention on the Rights of the Child (CRC) and the more recent UN Convention on the Rights of Persons with Disabilities (PWD). These project findings should be considered within the framework of the social model of disability within the broader context of children's rights. The social model of disability is the basis for the movement globally towards a social inclusion model for persons with disabilities. The Convention on the Rights of Persons with Disabilities was unanimously passed at the 61st meeting of the United Nations General Assembly on December 13th 2006. Since then, the convention has been ratified by 25 countries and signed by 128 countries, Viet Nam included. The convention was adopted with a view to promoting and protecting the full enjoyment of human rights and freedoms of persons with disabilities. It covers all aspects that need to be created, improved or reinforced in order to make sure persons with disabilities can fully participate in life on an equal basis with others.

The social model of disability makes a clear distinction between the impairment itself, such as a medical condition that deems a person unable to walk, and the disabling effects of society in relation to that impairment. In simple terms, it is not the mobility impairment that prevents a person entering a building unaided, but the existence of stairs that are inaccessible to a wheelchair-user. The key concept is that society disables people. In other words, "disability" is socially constructed. The social model puts the person at the forefront. It emphasizes dignity, independence, empowerment, participation, equality, choice and privacy. The aim is to see the person first, not the impairment. The social model of disability focuses thus on changes required in society, in terms of attitudes, social support, information and physical structures. The social model also outlines the potential of disabled people to contribute to society and add economic value, if given equal rights and suitable facilities and opportunities as others.

The social model is often contrasted with the medical model which sees disability as synonymous with impairment. This model focuses on diagnosis, prognosis, treatment and prevention in the context of disabled people being viewed as medical problems. Its focus is not on the way someone with impairment lives his or her day-to-day life. A consequence of the medical model is that it inspires pity and charity from society, rather than inclusivity.

The availability of data on children with disabilities is critically important in efforts to make them visible on national policy agenda. Therefore, obtaining reliable data and information on children with disabilities has been a major challenge to some extent due to the different definitions of children with disabilities used by different government agencies and limited awareness on their needs and rights.

Therefore, research was required to understand capacity gaps and to inform policy development, as well as to inform communications development that can change both individual and social behaviour. The purpose of this research study is thus threefold. Firstly, to understand the knowledge, attitudes and practices (KAP) of CWD and their families, including their main issues and expectations, and the barriers they deal with in their day-to-day lives. Secondly, to understand the perceptions of the community towards CWD; how they see them and understand their problems. Thirdly, to understand the role of stakeholders (key governmental and non-governmental) in this area; how they help CWD and their families; their main activities, and whether or not they have enough support and tools. The geographical area the report covers is representative districts and communes of Da Nang city. This will provide a holistic view of the situation and the foundation from which to drive an advocacy and communication strategy.

BACKGROUND

Context of Da Nang

Da Nang is the largest city in the central Viet Nam region, and the region's centre for economics (port and industry), education (5 Universities) and culture (Cham and My Son). The latest census results for Da Nang show that it has a total population of 887,069, making it Viet Nam's fifth largest city. Nearly ninety percent of the population is urban, with the urban to rural population at 770,499:116,570. The main ethnicities of Da Nang are Viet Nameese (Kinh), Chinese, Co-tu and Tay.

Da Nang typifies the many cultural traits specific to the central region. The central part of Viet Nam belonged to the Champa kingdom (7-15th century) well before the Viet Nameese entered the region. From early on, the Cham people were the first to engage in contact with other Asian cultures (notably Japanese and Chinese) and Western culture through merchants and Christian missionaries. This diverse exchange and contact between cultures has influenced the Da Nang people. They are known for being open to new influences, industrious and resilient in nature. The central region is also influenced by extreme climatic conditions with periods of long lasting floods and drought. This geographical influence further draws on the resilient nature of the Da Nang people, who live in a simple way that allows for quick recovery after times of hardship.

Da Nang is classified as an industrial zone and has port facilities to handle container traffic. Over 5,000 factories/production facilities are located in Da Nang. The breakdown of jobs includes self employment (50%), working for private companies (26%) and working in the government & administration sector (15%). The city has been experiencing rapid economic growth as illustrated by the 2008 growth figures below:

Table 1: Da Nang Economic data (2008)

GDP	+11% (versus + 6.2% national GDP growth)
Exports	+ 20%
Industry & construction	+17%
Investments	+19%

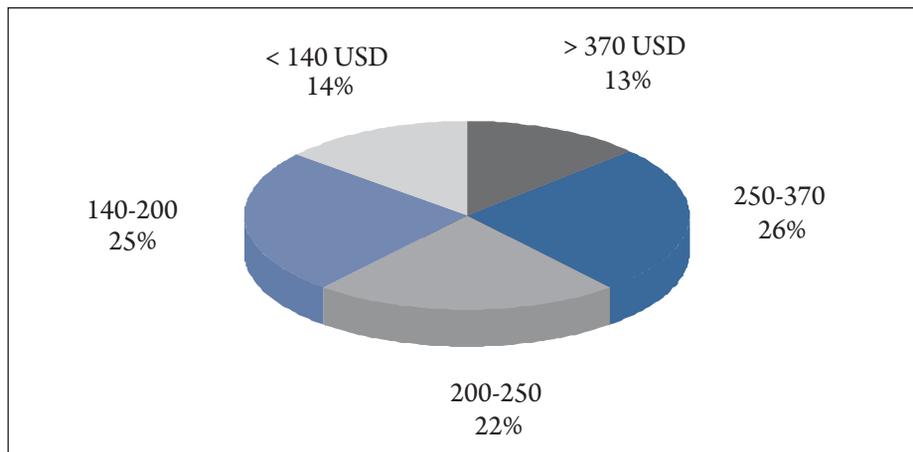
With this rapid growth and urbanization come the major changes and challenges facing Viet Nam today. Economic growth and rapid urbanization put enormous pressure on the ability of infrastructure, such as transport, to support this growth. Disadvantaged groups such as the urban poor population living in the city and women, for example, can easily become further challenged, if their situation is not carefully monitored and managed.

The Da Nang population can be divided in to 5 classes in terms of monthly household income:

Two extremes are found: 14% poor < 140 USD/household/month and 13% wealthy > 370 USD/household/month. 3 medium classes make up the rest of the population as seen in the chart below:¹

¹ Source: TNS has been tracking monthly household income through its longitudinal VietCycle study since 2001 given there are no official wealth distribution/SEC figures in Viet Nam. The 'household affluence' segments were initially set-up in a census style study conducted in 4 key cities of Viet Nam.

Figure 1: Household income- USD/household/month



According to DOLISA Da Nang, at present in the region there are 33,000 households living in poverty -19% of the total number of households. By the end of 2009, the city of Da Nang aims to reduce this number to 15%.

Context of PWD and CWD

Viet Nam has quite a high number of children with disabilities– including those affected by chemicals left over from Agent Orange. Estimates put the number at around 1.2 million². There are no statistics specific to Da Nang. There is a general lack of detailed and up-to-date statistics in this area. The lack of data on CWD's has been noted in all previous studies conducted in this area.

A survey by MOLISA in partnership with UNICEF in 1998-1999 on children from 0 – 17 years old showed that there were about 1 million CWD's in the whole country, accounting for 1.4% of the total population and 3.1% of the total children's population. On average, of every 5.7 households there was one family with CWD. Mobility disabilities were the most prevalent (22.4%) followed by speech impairment (21.4%), behavior problems (16.2%), visual impairment (14.6%), hearing impairment (9.7%) and intellectual disability (3.6%). Most CWD's have multiple disabilities. About 50% of CWD's living in the community and 90% of CWD's living in sponsor centers and had severe disabilities. 6.5% of CWD's in sponsor centers were abandoned by their own families, 2.6% orphans and 9.1% had no relations with their families. A majority of CWD's lived together with their families (95.85%) and had a care-giver. Half of households with CWD had great financial difficulties, thus could not provide adequate conditions for the children to rehabilitate their body functions and study.

A review of past studies relating to CWD and consideration of the findings of this study reveals that little progress on core issues has been made. The same issues and recommendations that came up in 2001 for example: lack of a co-ordinated national strategy informed by easily accessible and accurate statistics; the lack of integration in to inclusive education; stigmatization related to ignorance at a community and family level; limited access for CWD to public services such as healthcare, education, culture, entertainment, transport are recurrent themes of this study³.

2 MOLISA reports 2008.

3 Research on CWD and their families in Da Nang, Knowledge - Attitudes – Practices, TNS for UNICEF 2009

RESEARCH METHODOLOGY

Methodology and Methods applied

A two-phase research design was necessary to meet the information needs. A human rights based approach was adopted across all aspects of the project to ensure a representative perspective was gained. This approach incorporates the following:

- **Participatory assessment:** respect different views of stakeholders and right holders – children, CWD's and their parents.
- **Non discrimination:** reflect the exclusion-discrimination of CWD's across ages, gender, types of disabilities.
- **Gender/Age:** male and female; adults and children's points of view.

For the qualitative phase, respondents were recruited utilising the support of DOLISA and UNICEF.

Quantitative phase - Community survey

The main objective of the Community survey was to measure the perceptions and KAP of the community of Da Nang towards the CWD and their families:

- Familiarity with the problems met by CWD and families, their needs and expectations
- Support to facilitate integration of CWD in to the commune
- How they see the activities of GOV and NGOs
- Use of communication channels and media habits

Face to face interviews were conducted amongst the general population, aged 18-69 years across the 7 districts of Da Nang: Hai Chau, Thanh Khe, Son Tra, Ngu Hanh Son, Lien Chieu, Cam Le and Hoa Vang.

The sample size was $n=150$ and quotas were applied by gender (50/50 male to female) and district ($n=20-25$ per district). The sample design and sample size of $N=150$ was finally decided upon as a statistically robust enough sample to give sound analysis at a general overview level representative of the broader community. A higher sample size would have been necessary if detailed analysis was required at the district level for example. The questionnaire was prepared in collaboration with UNICEF and took approximately 35 minutes for respondents to complete.

Qualitative phase

Research with CWD and their families

The central part of the study was a qualitative phase with CWD, parents of CWD, children without disability and the relevant stakeholders.

The objective of the component with CWD, parents of CWD, and children without disability was to get a clear understanding of:

- How CWD and their families live with disability
- What are the main problems in their daily lives, their needs and expectations
- What makes CWD happy children, what makes them feel like other children
- Other children's view of CWD

This phase was composed of two sections: Ethnography with CWD and their families and focus groups with Parents of CWD, as well as one focus group with children without disability.

Ethnography with CWD and their families

Five children and their families were recruited for the ethnographic phase. The families were recruited in representative districts of Da Nang with representation across the main disability areas, as shown in the table below, by recruiting one child/family per main disability area.

The research team consisted of two to three ethnographers per session, who visited with the children and their families for a period of 4-5 hours per session. A structured topic guide facilitated observation of the child, the family and the surroundings in an active and detailed manner. Incentives were given to the families to thank them for their participation.

Table 2: Ethnography

	Name	Disability	Age
1	Thin	Hearing impairment	6
2	Tung	Visual Impairment	9
3	Ngoc	Mobility impairment	16
4	Thang	Intellectual disability	17
5	Chau	Multiple disabilities	13

Focus Groups with Parents of CWD

Four focus groups with parents of CWD and one with children without disability were held as per the table below.

The parents of CWD were recruited in representative districts of Da Nang with each group consisting of 7 participants incorporating a mix of male and female parents of children of different ages. The group discussions lasted 2 hours. For the focus group with children without disability, the group consisted of 7 participants; a mix of boys and girls aged 6-10 years. The group lasted 1.5 hours and incentives were given to the children to thank them for their participation.

Table 3: Focus group discussions

	Group	Child Disability	Age of the Children
1	Parents	Hearing impairment	0-18
2	Parents	Visual Impairment	0-18
3	Parents	Mobility impairment	0-18
4	Parents	Intellectual disability	0-18
5	Children without disability		6-10

Stakeholder Interviews

The objective of the Stakeholder interviews was to investigate the viewpoints of relevant authorities and agencies concerning CWD and their families to understand their perspective on the current situation of CWD and their families in Da Nang, their involvement and support, and their perspective on necessary future actions.

10 in-depth interviews were conducted as per the table below, each lasting approximately 45 minutes to 1 hour.

Table 4: Stakeholders

Stakeholders	
Ministry of Health	Da Nang Department of Health
Ministry of Education and Training	Da Nang Department of Education and Training
Ministry of Labour, Invalids and Society	Da Nang Department of Labour, Invalids and Society
National Coordinating Committee on Disability	Da Nang Department of Construction
Viet Nam Association of Agent Orange	UNICEF

Collection of IEC Materials

An inventory and evaluation was made of materials collected in Hanoi and Da Nang from all relevant stakeholder groups (State agencies and NGO's) including regulations and guidelines, as well as books, brochures and magazines addressing disabilities and related issues.

Analysis conducted

Segmentation analysis was conducted on the community survey data with the aim of:

- better understanding the different perceptions found within the community
- better defining and prioritising communication strategy
- orienting the recommended communication actions: types of actions and channels

The segmentation analysis consisted of dividing the sample in to relevant target groups based on their perception of CWDs (what people think the CWD need from society; their issues and problems, their opportunities, etc). People who expressed the same patterns of answers on the attributes selected for the analysis were grouped in to the same cluster using the statistical method of cluster analysis. Each cluster was then quantified and given a name (subject to interpretation) based on the attributes that define it.

RESEARCH FINDINGS

1. Knowledge, attitudes and practices

Issues and influencing factors in relation to knowledge, attitudes and practices towards CWD were found to be consistent at a family and social level. Likewise the stakeholder perspective reinforced the key issues found. The family is the most important of all social units in Viet Nam and is the foundation of society, thus the consistency in findings at an individual, family and social level is commensurate with this.

The circumstances under which the child acquired their disability and the type of disability the child has, within the overall issue of defining disability are key factors. Family structure, gender issues and economic circumstances also play a key role in determining knowledge, attitudes and practices, and thus positive or negative outcomes for the CWD.

1.1. Circumstances under which the CWD gained their disability

The family perspective

Relating to the circumstances under which the CWD gained their disability, we found four different types of situation in the ethnography, which impacted the general mindset and behaviour of the parents and families involved. Whilst these situations are detailed below, we can generally note that if parents are in some way prepared for having a CWD, they are better able to deal with the situation and more likely to form a more positive mindset and subsequent behaviors. This highlights a key issue around lack of knowledge in the community as to disability in general, and a capacity gap within the healthcare system, where education, diagnosis and early intervention are clear issues. More sensitive statistics and data collection could be used to monitor this situation over time.

Where disability was expected due to complications during pregnancy, e.g. getting sick, overuse of antibiotics, premature birth etc, parents seem better prepared to deal with the situation. At the same time, they also receive more encouragement and support generally.

“I don’t know what happened, but maybe it was because my wife worked extremely hard during pregnancy. This may have affected her health and caused the baby to have problems at birth”

“My child was born 2 months premature, after that he was slow to develop”

- Group of parents of children with intellectual disability

Where the disability occurred later on in life, e.g. the child suffered from some kind of sickness such as high fever or Japanese encephalitis without being treated in time, the parents and families are able to better cope with the resulting disability, with the feeling they are lucky their child survived the sickness.

Where problems were not discovered until immediately after birth, either clearly visible right after birth or found shortly thereafter by the doctor, parents are mostly left in a state of surprise, pain and confusion.

Where the disability was identified later, e.g. family takes child to the doctor in the early months of its life; parents are left feeling shocked and lost.

“When my baby was just one month, I carried him to the eye hospital. My husband and I called for the doctor. The doctor said: “what could I do, he was born like that”. Hearing that, we just broke down in tears!”

- Group of parents of children with visual impairment

“Right up until my child was 3 years and all she said was ‘ah’ and ‘uh’, we just thought she was late to speak, we had no idea something was wrong!”

“I didn’t know until I carried my baby to a check-up and the doctor said my child was “born deaf”.”

- Group of parents of hearing impaired children

When asked about healthcare issues related to their child, most parents showed a lack of understanding of their child and their child’s needs. The families demonstrate the lack of healthcare preparation and guidance missing in Viet Nam to prevent many of the causes that lead to disability of newborn babies. Many situations that arise are considered to be unusual complications or due to health and nourishment issues of the mother during pregnancy. Many other situations arise due to a lack of guided observation of development after birth. Other situations arising only after birth are linked to diagnosis issues.

With the passage of time, most parents tend to accept their child’s situation. They resign themselves to the notion that “it’s my child, I have to raise it”, and feel that their care is both a responsibility and a necessity, “there is no other way”. This passage of time can initiate a shift in mindset and behaviors from unsure or negative, to an accepting and in some cases positive shift.

The stakeholder perspective

Prevention is certainly a priority improvement area. There is an urgent need to start to develop prevention services. According to UNICEF, many cases of disability could be prevented with a proper national program, new born screening and early intervention. Some families in Da Nang have more than one child with disability; very often those cases can be prevented if there is medical genetic counseling to explain the risk of having a second baby with the same problem.

Healthcare capacity, addressed later in this report, is also recognized as a key issue. Lack of facilities and equipment in hospitals and healthcare centres, as well as a lack of rehabilitation professionals in Da Nang, are core issues.

1.2. Type of disability the child has/ overall issues of disability definition

The family perspective

According to parents of CWD, the community in Da Nang adopts a broadly positive attitude towards CWD and their families. It is their nature to give ‘their helping hands to the less unfortunates in the community’.

Ngoc’s mother sells vegetables in the market in the morning and Thang’s mother sell cakes in the afternoon. Ngoc studies on her own in the morning, the house is kept an eye on by

neighbours. Thang often wanders around the ward in the afternoon. Neighbours also help to watch the house and play with him.

- Ethnography 3&4 – family of mobility impaired and child with intellectual disability

However this broad positive attitude has limitations and we can see underlying issues of ignorance and stigmatization that have been found in past studies. For example, at some public holidays, where luck and good fortune is paramount, taking children with disability out in the community can be taboo, ie. considered bad luck; a harbinger of ill fortune.

“When I go to the park or go to see firework, I will take her along but I do not dare to take her along during Tet holiday since I’m afraid people forbid it.”

- Parents of children with visual impairment

Whilst these broad issues exist, a switch to a positive mindset is currently mostly related to what type of disability the child has. If the child has a disability which is more accepted by the community (generally one which is both more visible and/or in cases where the child can more easily comply with accepted norms of behaviour), the shift to a positive mindset and positive behaviors appears more likely. These families then strive to create the best possible conditions for integration in to the family as well as the community. During discussion, parents of these children show great pride and confidence in their child’s progress and achievement, and the positivity is also reflected in the child.

Different types of disability also receive different attention and empathy from the community as well as the families themselves. Hearing/visual/mobility impairment are more easily accepted by and integrated in to the community: these CWD are more likely to have friends from school and the community who often come to visit them. They are more likely to communicate well with their friends without too many language barriers or behavioral obstacles. Sympathy and sharing of the neighbouring community can significantly contribute to the development of these CWD.

Parents of children with hearing and sight impairments do not refer to their child as “disabled”, but rather “decreased function in sight and hearing”. These are children who are considered by parents as “only slightly impaired”. These parents express a great deal of frustration when their child is labeled “disabled” or when popular terminology such as “dumb”, “deaf”, “blind” is used. The majority of these parents have at least a basic understanding of the condition of their child’s disability and believe their children can be partially rehabilitated with the use of tools such as hearing aids, for example.

“When I hear people say hearing impaired it sounds so much more gentle, when I hear ‘mute’ and ‘deaf’ it really gets me down”.

- Parents of children with hearing impairment

“Once I brought my child to the market, a lady selling goods saw me talking to my child and asked: “Is your child deaf or something?”. Afterwards, my child didn’t want to have any contact with that lady”

- Parents of children with hearing impairment

“My son really hates it when someone calls him “blind”. It takes him a long time to get over something like that.”

- Parents of children with hearing impairment

"My heart aches when I hear people say 'the blind kid'."

- Parents of children with hearing impairment

The situation is very different for children with intellectual disability. These children may represent as very quiet, silent and are easily teased by children with no disability. Or the opposite can occur- they exhibit what is considered bad behaviour, such as 'beating up others, naughty, easily shout and cry out' that makes people feel upset and negative towards them and their inclusiveness in the community.

Children with multiple disability have the hardest problems for integration: children in the community do not want to play with them; their communication capacity is more limited; it is hard for them to move around and their appearance is generally a barrier for acceptance by others in the community.

Parents of children with disabilities such as mobility impairment, intellectual and multiple disabilities, generally express more concern and pessimism whilst discussing their child's situation. These parents state there is a lack of understanding of 'disability' from people. Words like "mobility problems", or "intellectual disability" are more easily accepted by these CWD and their families. Popular terminology such as "slow" or "down" reinforces their pessimism and feelings of isolation.

Overall, when parents of CWD hear the word "disability", most tend to think of something specific that can be visibly noticed and recognized, for instance: "a deformed part of the body". This perception is linked to more severe "deformities" including victims of Agent Orange as many stated in the group discussions...*"They are people who lost a part of themselves so they are called disabled"*

The word "disabled" here indicates a "function" or "portion" of the body that is deformed and consequently "disabled", meaning someone who cannot do something. However, these parents also recognize that the word "disability" is not a fully encompassing term. There are many different types of disability with different levels of severity.

"Many people don't understand, they think my child is missing an arm or a leg. Or they think of Agent Orange. We shouldn't use the word 'disabled', we should say 'kids with special circumstances"

"When I hear the word "disabled" I am hurt"

- Group with parents of children with visual impairments

The social perspective

In general terms, children without disability have a caring and supportive attitude towards CWD as they are taught at school and in the family that "these people are pitiful and need help". Thus they are inspired towards feelings of pity and charity rather than necessarily inclusion. They exhibit a range of attitudes and behaviors, from being conscious of helping out CWD, especially at school, such as copying down lessons for them, talking to them, helping them up and down stairs and escorting them home.

"You should help nurture them and respect them. Don't cause problems for them or tease them"

"In my class there is a kid with a disabled leg, he cannot go outside during break times, sometimes we have to help bring him outdoors to talk and play with us."

- said by an 7 year old boy in the group of children without disability

In the community or in the neighbourhood, children without disability also sometimes mix and interact with CWD. For these children, they expressed seeing CWD sometimes as especially 'kind, cute and tolerant of others'. When it comes to mention of adults with disability and people with severe disability, which they do not have a chance to meet directly, the cerebral-palsied for example, they express curiosity, fear and ignorance, thus expressing that their attitudes and behaviour are also impacted by type of disability and familiarity.

"I was scared but I did not tell anybody"

"She is blind and does not see anything. She got on the stage to sing. My friends dragged me to the corner, pointed at her and laughed"

- A group of children without disability

Some children without disability still show some misguided behaviour towards CWD, primarily by teasing and laughing at them, and it is again evident that this is more directed at children with intellectual or multiple disabilities.

"Thang sometimes is teased or made fun of by misbehaving kids in the neighborhood; they even tried to tear his clothes and upset him greatly! People in the neighborhood saw it and told me so I had to run home to rescue him...!"

- Ethnography #3 – Family of child with intellectual disability

The children themselves reflect on the behavior of children who make fun of PWD and CWD as "indecent", reinforcing the broader positive attitude noted earlier related more to pity, charity and notions of correct community behavior, rather than a feeling of acceptance, inclusion and respect.

"These people do not look like anyone, people invite others to go and look and stare to make fun of them. They are not good people"

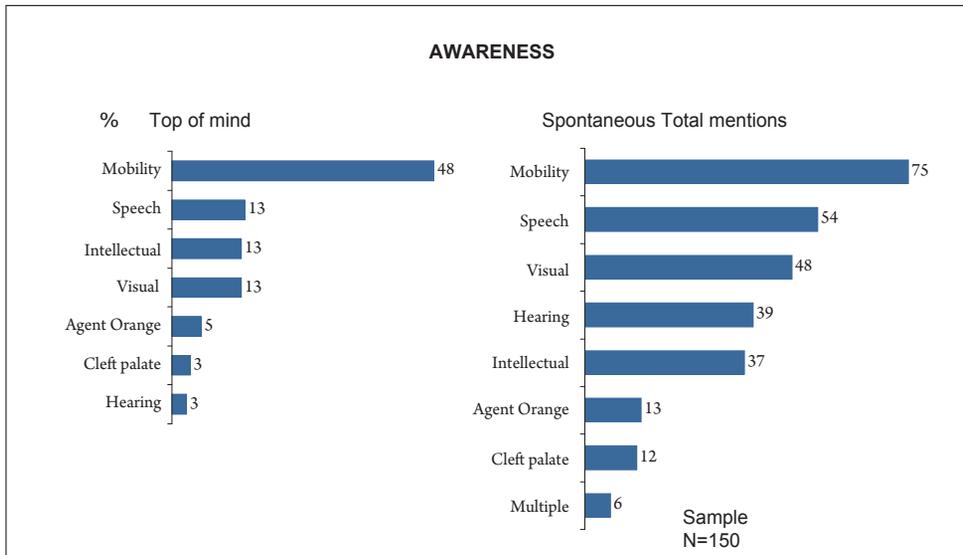
- A group of children without disability

In general however, it is positive to see that education about attitudes towards PWD and CWD, both at school and in the family, can have a positive impact on the children's attitude and behavior. This contributes to bridging the gap between CWD and other children in the school, as well as in the community, and thus indicates the opportunity to communicate and educate around more inclusive attitudes.

In the broader community survey, we saw a validation of community awareness and comfortability with the more obvious, physically visible impairments versus a much higher level of uncomfotability with intellectual and behavioral disabilities.

Physical/mobility disability comes clearly first in the mind of the broader community - 48% top of mind awareness (first disability mentioned by the respondents) and 75% awareness in total; followed by speech impairment, visual impairment, intellectual disability at the same level spontaneously - 13%. Other than for mobility, the top of mind awareness is quite low, further reinforcing the lack of familiarity and knowedge of this area across the board. In total mentions (all disabilities mentioned by the respondents); the ranking is as follows:

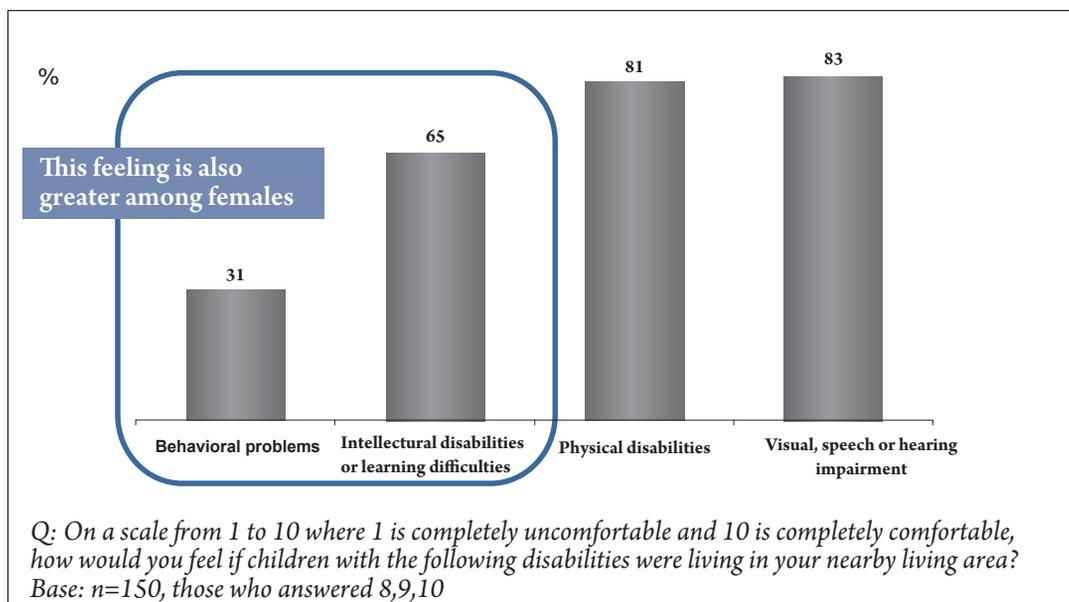
Figure 2: Awareness toward kinds of disabilities



When being asked if they know CWD, 85% of respondents declare they know at least one child with physical/mobility disability, 60% children with speech impairment/intellectual disability and 50% children with visual/hearing impairment. Most of them have contact with the children at least once a month. 91% know the children from the community and 9% from relatives, colleagues or neighbours, thus this knowledge is more distant than in their close community.

When it comes to the broader community's senses of comfortability, we again see clear differences across the different types of disability. There is much less comfortability with behavioural problems and intellectual disabilities. We also see a higher level of uncomfotability from females. Thus whilst we find that females with disability are more marginalised, we also find they have a stronger level of uncomfotability with the more stigmatised types of disability

Figure 3: Feeling of people when knowing CWD's live in their area



The stakeholder perspective

The experts interviewed tend to agree that in the community there is more discrimination towards CWD with intellectual and multiple disabilities, or more severe disabilities in general.

“It is of real concern and shown by everyone in the community. Usually, children who suffer from less severe disabilities still interact with the community like any other child. However, this is not the case for children who suffer severe disabilities. We need to create conditions where all children can play and converse with their friends.”

“A number of kids, such as those with intellectual disabilities of a less severe nature, can still function quite normally in society. Some kids with mobility impairment can still go to school. But for those who suffer severely, then it’s quite difficult for them to do anything. In Da Nang we encourage the parents of children with less severe disabilities to allow their children to go to school as normal. As for children with mobility issues, most families must take care of them by themselves.”

- Representatives of DOLISA

“People with CWD do not want to accept their child has a disability unless it is clearly visible to other people. Through dealings with teachers we have noticed that children are labeled disabled by their teachers, not by their parents. This is because the majority of people who have CWD still want their child to be able to integrate into society. There was a lady with a four or five year old child who couldn’t speak, but she would not accept sending her child to a special school. It’s a barrier. This is the mindset of parents who have CWD, for other parents the mindset is not like this.”

- Representative of DOET

International stakeholders, in this case UNICEF, reinforce the Social Model approach can help improving integration of all CWD.

“Disability is different but also all of us are different: we have different eye color, different cultures and traditions... all people are different and we should respect these differences. We should not think of normalizing them and bringing them to our standards, we have to create an enabling environment for everybody to feel equally important. We should shift the medical/rehabilitation model. For example, if someone has only one leg, you can have prosthesis to help him to function properly, but you cannot bring him to the norms, there is the need to create an environment that is enabling him to function. This should be the key message to deliver to the society to change their mentality and attitude”

- UNICEF

Most departments and organizations interviewed for this research were in unanimous agreement that at a national level and regional level there is still no standard or criterion for accurately classifying different forms of disability. No consistent numbers were given by any stakeholders during the in-depth interviews in both Ha Noi and Da Nang. However, it is confirmed that there are surveys being completed across the country which are expected to be available in the near future which can help better plan and develop strategies and policies on PWD in general and more specifically on CWD. The classification of disability is still under on-going discussion. The differentiation between stakeholder’s terminologies around classification is noted in the table below (as described in the stakeholder interviews)

“Recently, according to a legal draft agreement on PWD presented to the national assembly, PWD can be grouped as follows: mobility impairment, hearing impairment, speaking impairment, intellectual disability, seeing impairment, multiple disability and other types. So, we can break them down in to seven groups...”

- Đại diện của Bộ Y tế

Table 5: Current Understood (not official) Differentiation between MOH and MOET Classification Terminology

MOH	MOET
Mobility	Mobility
Sensual (Hearing & Visual)	Hearing
	Visual
Intellectual	Intellectual
Behavioral	Multiple

In reality, whilst policies and legislation related to People and Children with Disability have or are being put in place, there is a clear lack of unanimity between departments, committees and relevant agencies in relation to the situation of CWD. This creates large problems for development of policies and programs aimed at improving the lives of CWD and their families in general.

1.3. Family Structure

We can also see a relationship where families with a divorced or widowed parent demonstrate different mindsets and behaviour. In divorced families or families where a parent has passed away time spent for the child is restricted. Observations from group discussions and ethnography show that males in the family play an important role in providing motivation, hope and encouragement to the family unit. Most of the men interviewed showed a calm and clear minded attitude in seeking solutions for their children. However, those family situations in which the father leaves, cause a great deal of pain and suffering for the mother and the child, and subsequently a much less positive set of attitudes and behaviour are found in these families.

1.4. Gender issues

Gender discrimination was observed to exist in several families. There is a strong perception that a boy with a disability still offers prospects for the family (e.g. a future bread winner; can have a family in the future; can help expand a family into bigger relations), whilst girls are seen more as a liability. It is felt girls are of no good to others if they have a disability and can only take care of themselves in the future, whereas a disabled son is better than no son at all. Girls with disabilities are thus more likely to receive more negative attitudes and behaviour exhibited to them at both a family and society level, and therefore have more barriers to deal with than boys.

“It is just like what he wanted, my husband said that he would like a boy, even if the boy is with disability, it has to be a boy, even we already have 6 girls in our family, and then, the only boy in our family is born with disability as my husband wished”

- Parents of children with mobility impairment

"If she cannot learn at school, she still must learn to do something because she is just a girl. Girls need to learn to take care of themselves!"

- Parents of children with intellectual disability

1.5. Economic circumstances

The family perspective

For families with lower household incomes, their issues are much more apparent. They exhibit even less knowledge on how to care for their CWD, and their mindset and behaviors are more focused around day to day survival, and subsequently the daily needs of their CWD. They have low awareness of any support programs to assist rehabilitation in to the community. They either lack knowledge on, do not have the means to participate in, and/or feel a sense of hopelessness around specialized support for their children. When they do have expectations, they are simple and reflect their more day-to-day survivalist short term view.

"My family raises my daughter like raising a dry plant. We try to create the best conditions for her, we don't ask for a lot, we just want her to recognize her mum and know how to eat for herself"

- Ethnography # 1 – Family of child with multi-disabilities

"I just wished I had money to take my child to Hanoi or Saigon, I just want to know how deaf my child is, and why she is how she is."

- Ethnography # 5 – family of child with hearing impairment

The ability to meet the needs for support and care of CWD is largely influenced by each family's situation, size and particularly their economic capacity.

"At one stage I ceaselessly took my child to rehabilitation but later on I just didn't have the money to continue, I just have to leave her at home while I go off to work. Slowly she started to learn how to stand, if I hold her I can take her around a bit. But really she can't do anything"

- Family of child with mobility impairment.

It is often the case in large families where the parents, absorbed in working to earn money for the household, do not have time to take care of their children who are then left alone at home. The child therefore must be more independent in life.

According to parents of CWD, authorities at the district and commune level in Da Nang sympathize and provide support to the families. It seems however that support largely depends on the enthusiasm of the ward and commune staff. In the wards where there are enthusiastic heads, the heads usually visit each family to enlist the names of those in need. They send the list to a higher level to be certified and the support is thus provided more easily to the people in need.

"The head of wards are very caring, they come to our family and see our child with some kind of impairment, then they help us to get support from the local wards!"

- Parents of children with Intellectual impairment.

A few families said that the assistance is not consistent and they are even unaware of criteria the support is based on.

“Support is varied among different wards. It is not the same everywhere. In Tuong Lai school, they show more care. They would lower food expenses by VND 50,000 to 100,000 for poor families.”

- Groups of parents of children with hearing impairment

“I think the authority has not been deep nor realistic. They rejected my application because they don’t think we are poor enough just by looking at our house”

- A father of two children with intellectual impairment

In order to receive the support, the families must be ranked as poor households. The poverty ranking, however, varies by locality. It is said that there has not been a consistent poverty standard in Da Nang in general.

There are wards where families receive much less care. They themselves have to ask for the certification paper and to fill out complicated documents in order to receive support without any assistance.

“There should be less complex procedures so that people can receive the support directly, not that doing such complex procedures just for a few dong.”

- Group of parents of children with intellectual disability

Although families of children with disability expect material support, parents stated that ‘the way’ support is provided is even more important than how much the support is. Mental support plays an important role. What families want is care, support and sympathy from authorities on different levels so that they do not feel discriminated against or isolated. This is also highly variable.

“Care should be material or mental but the purpose is to mitigate the pain of parents who unfortunately have children with disability. Actually the money is just nothing”

- Parent of children with intellectual disability

For families with better economic conditions, they want and have the means for their child to have access to the most advanced equipment, even if costly. They have better access to and tend to listen more to professional advice. For example:

- Hearing impairment: they take the child to be examined, to identify the level of severity, then purchase a hearing aid
- Visual impairment: they send their child to the Eye Hospital to stimulate the senses or try for an operation
- Mobility impairment: they bring the child to a large hospital in Hanoi or HCMC where it is believed they will have better healthcare services and treatment. Or to the Da Nang rehabilitation centre

These parents are also more likely to take part in courses on rehabilitation and inclusive education. On the other hand, ‘word of mouth’ or traditional remedies are still frequently adopted by this segment, demonstrating that knowledge and education issues cut across the board.

“People said that Nhong bird is a very good kind of traditional medicine. So that, when there is a person who came and brought Nhong birds, I bought two birds with the price 4 million dong (approx. 250 USD), those birds were still alive. People say Nhong birds can speak, so I thought maybe my child would be able to speak. I just listened to whatever people told me, I didn’t think of anything else.”

- Group of parents of children with hearing impairment.

The social perspective

When asked to rank their level of agreement with challenges faced by families of CWD, 83% of the people interviewed believe that the main difficulty (out of a range of difficulties covering the spectrum of challenges faced by parents of CWD), is their financial constraints in relation to meeting their children’s specialized healthcare needs.

The stakeholder perspective

It is acknowledged that the circumstances of CWD greatly depend on the economical situation of each individual family. According to MOET and DOLISA, many CWD’s come from lower income families, or are at least pushed into difficult economic situations due to having a CWD.

“The majority of these families are poor or have tough economic circumstances. Instead of focusing on making money, they have to take care of their CWD who have higher standards of expectations and require more attention. They are living uncomfortably with this, so they cannot go out and get work. This is the consequence of having a CWD, not the consequence of being poor.”

- Representative of MOET

“Many children who have parents without stable jobs and who are poor receive less care from parents. On the other hand, families in better economic situations can afford to send their children to specialized schools in order to help them integrate into the community.”

“It’s clear that higher income families have better knowledge and are better prepared to deal with these kinds of issues such as early intervention and early identification in order to help rehabilitation.”

- Representative of DOLISA

UNICEF expressed a particular concern about the vicious cycle of disability and poverty being recognized, i.e. that all in the community are vulnerable. The link between disability and poverty is strong throughout the world. Disability is both the cause and the consequence of poverty. Disability and poverty together contribute greatly to increase the vulnerability and social exclusion of the populations attached to them.

It is important to see how the circle starts and closes in order to find a way to break it. Take poverty as the starting point. As was seen in this research study, poverty usually means:

- Poor nutrition
- Dangerous working and living conditions
- No or limited access to basic health care (e.g., health and maternal care, vaccination programs)

- No education and vocational training opportunities
- Poor hygiene and bad sanitation
- Lack of information about causes of impairments

Poor people are at a greater risk of becoming disabled than people who are not poor. According to UN Figures in *Overcoming Obstacles to the Integration of Disabled People*⁴ global causes of disabilities are as follows:

- | | |
|-----------------------------------|-----|
| ▪ Accident, trauma, or war: | 16% |
| ▪ Infectious diseases: | 11% |
| ▪ Non-infectious diseases: | 20% |
| ▪ Congenital diseases: | 20% |
| ▪ Other causes (including aging): | 13% |
| ▪ Malnutrition: | 20% |

Poverty can lead to many of these causes, which means impoverishment is the direct link to the status of impairment or disability. Disabilities caused by poverty are generally preventable if poverty is alleviated, education improved and quality health care boosted.

Disability can also lead to poverty since people with disabilities are stigmatized, discriminated and excluded from society on the basis of their status. As was seen in this research study, disability usually means:

- Social isolation and economic strain are increased, for the person with the disability and for the family
- Children with disabilities are more likely to die young or be neglected, malnourished, uneducated, and poor
- Women with disabilities are doubly discriminated against, on the grounds of gender and impairment: Women are illiterate more often than men with disabilities; women are more likely to be victims of physical and sexual abuse; and they often lack access to public and maternal health care
- People who did not get the chance of schooling and vocational training are likely to stay unemployed. Joblessness means even more poverty for the disabled person and the family

As the person with the disability, the family, and the communities sink deeper into poverty, and the vicious circle is closed.

2. Current systems and integration in to society

2.1. Social systems of support

The family perspective

Reflecting the point raised earlier, many situations were shared where the parents of CWD received none of the necessary consultancy or guidance required from health care workers regarding how to deal with their CWD in terms of treatment and support.

4 UNESCO sponsored report as a contribution to The World Summit on Social Development, Copenhagen, Denmark, March 1995

“They just told us to buy a hearing aid, but they didn’t say what type or if there are any differences between them. So, I just decided the most expensive one is probably the best one for my child.”

- Group of parents of hearing impaired children

There is a lack of general knowledge on healthcare about CWD for parents. Clearly there is a need for more and accurate information about CWD, causes of disabilities, and different types of disabilities for parents as noted, likewise, more training on prevention, early detection, and diagnosis, treatment and rehabilitation for both parents and healthcare practitioners.

We see evidence of a lack of facilities and equipment in most healthcare services centers and hospitals in Da Nang, a lack of specialised human resources and high services fees meaning limited accessibility.

Positively, we see parents are willing to take part in rehabilitation programs for their CWD and effective rehabilitation programs are implemented with positive results in some locations. However in reality, very few parents participate in training or coaching courses designed for families of CWD on matters concerning early intervention, inclusive education, rehabilitation, taking care of, etc. The reasons for this are:

- Limited information on training/coaching courses
- Lack of time: no means of travelling far (HCMC or Ha Noi), no one looks after the kids when adults are away
- Psychology: being afraid to make contact with others – weighed down by the psychological complexity of having a CWD
- Attitude: ‘let things run their course’; no positive view on the benefits of the training course. Not having positive view on the benefits that the training course can bring to their CWD, especially those with severe disabilities, where they believe their CWD cannot be treated nor cannot be improved.

The parents who have participated in training courses for CWD however have a more positive and empowered attitude, a better grasp of the child’s situation as well as knowledge and skills to improve their situation.

“Sitting here is for us to learn, the purpose is not for us but for us to transfer the knowledge onto others and to our children. About two years ago there was a conference at the Tuong Lai school that went for 2 days. That was for us and our children so we have to go!”

“For example, this child is deaf at 80 decibels so you use that hearing aid or you use an aid for 80 decibels, then 100 decibels. If you are deaf at 40 decibels then you use a an aid for 40 decibels, that’s the principle behind it. Also, you have to remember that the aid might not fit the child because they are too small or too big, if wind blows into the ear then the hearing aid has no effect”

- Group of parents of children with hearing impairment.

The stakeholder perspective

The MOH’s activities mainly aim at providing instruction and guidance to the DOH regarding policies, rehabilitation and training programs developed by MoH. They also provide support and training

courses to practitioners. The DOH Da Nang instructs organizations such as hospitals/medical centres to provide healthcare services and treatment for CWD in accordance with Decision 239 which includes activities such as rehabilitation for CWD, health check-ups, observations and reporting to higher levels. The Rehabilitation hospital in Da Nang provides both free rehabilitation services (community based rehab) and paid services for those who require specifically customized treatment at VND 500,000/hour (ie. the child's family comes in with a specific request for a service for their child). Da Nang DOH is also carrying out rehabilitation in the community performed by commune and village health workers and/or rehab collaborators. These health care workers are pioneers to carry out this type of support with cost, and have been trained extensively by MOH, DOH and other relevant NGOs.

Da Nang currently has received a relatively large amount of support for children and people with disability, though each program has not yet been evaluated. Whilst these programmes initially have had positive impact on improving the lives of people and children with disability, a lack of effective coordination between different agencies and organizations involved is recognized by different stakeholders as mitigating this positive impact.

It is also clear that despite many forms of support to CWD from the local authorities, they are still far from meeting the needs of CWD and their families in Da Nang.

"The situation for NGOs in Da Nang is one of too many cooks spoiling the broth. Because there are a great deal of NGOs operating in Da Nang. All these projects all promise the world to the locals but when they see no results it causes people to lose hope."

- Representative of DOH

The overall lack of consistency in the classification of disability makes this support less accessible to the CWD and their families

- Family income
- Household durable ownership or
- Housing types

The majority of respondents in group discussion and ethnographies reported receiving monthly financial support from the local authorities which ranges from VND 150,000 to VND 250,000 a month for each CWD / family

"A proposal has been made to MOLISA to increase the minimum amount to VND 200,000/month for each CWD"

- Stated by a representative of NCCD

There are no official criteria for allowing support to CWD in Da Nang. According to MOLISA and DOLISA, support is granted based on the severity of the disability and the family situation (income, housing). However, it seems that there are no standards, the decisions are taken on a case by case basis: priority may be given to children with multiple disabilities; in some cases hearing impairment may not be considered as eligible for support.

"In decree no. 7, people with severe disability who cannot work receive more here than anywhere else in the country. For example, the national regulation is VND 120,000-150,000, but the city provides VND 180,000-240,000"

- Representative of DOLISA

Concerning resources, UNICEF points out that the issue is not only the lack of funds but also the planning system, the allocation of funds from one sector to the other.

“If you prioritise the community-based solution, you can still shift some funds from one sector to the other one. Instead of supporting the construction of a new social protection center, you can reallocate the funds to community-based solutions, so that many CWD and families can receive support. Of course there will be a need for more funds, but in the situation where you have limited funds, it depends on the way you plan and prioritise.”

- UNICEF

More broadly, MOLISA is coordinating with MOET, MOC and NGOs to implement the UN International program “BIWAKO MF+5” towards a more inclusive, un-intruded society for the people with disability in the Viet Nam. The BIWAKO program includes seven priorities:

1. Organizing self-help groups of PWD and the association of families of PWD
2. Women with disability
3. Early detection, early intervention and inclusive education for CWD
4. Training and vocation, including job creation for PWD
5. Accessing public transportation and public facility
6. Accessing information and telecommunications
7. Eradicating poverty through advanced capacity, social welfare and life long programs

The BIWAKO activities are mainly carried out in HCMC and Hanoi. In Da Nang, the following actions are being carried out:

- Program 65: for children in difficult situations, including CWD
- Degree 67: support for people in need of social welfare, including CWD

According to DOH, in reality, whilst policies and legislation related to People and Children with Disability have been put in place, there is a clear lack of unanimity between departments, committees and relevant agencies in relation to the situation of CWD in Viet Nam in general, and Da Nang in particular. A clear strategy has still to be defined, aimed at increasing effectiveness of dealing with CWD. Other stakeholders also recognise the need for co-ordination.

“Within the NGO group, they try to coordinate the activities, health-education-protection-jobs-vocational training, so that they can divide the responsibilities and prevent the overlap.”

- UNICEF

2.2. Education

The family perspective

We found a majority of parents hope to send their CWD to special schools. They feel these are environments of more specialized and adapted care, they have the facilities and materials necessary, including specially equipped rooms for different forms of disability. This allows kids to share and

sympathize in an environment that favors equality. However, parents complain about the high tuition fee for this form of education. Many lower/middle income families in Da Nang do not have the financial capacity to send their children to these special schools.

Most parents in Da Nang are aware of inclusive education yet they are quite reluctant in their feelings towards this type of education. They feel their child is not receiving the necessary attention, the child is likely to have a feeling of being left behind amongst the other children, CWD do not have an individual place to play or conduct their day to day activities, community services aimed at supporting CWD for inclusive education are very limited and that ultimately, CWD are given no preference or support when using public transport to get to school.

In the minority cases where inclusive education is being participated in however, the outcomes appear positive to all concerned:

“He learns in an inclusive school. His friends love him very much. They see Nam has the disability and sympathize with him. They love and protect each other very much.”

- Parents of children with visual impairment

“Not being able to hear anything people say would make me so sad and lonely”

- Emotional compassion from group of children without disability

According to the Department of Education and Training, every school in Da Nang offers inclusive education. In reality, not all disabilities are easily accepted. The main obstacles seem to be both school and community attitudes and perceptions rationalized with practical barriers: CWD require more support from classmates; more teaching tools are required and the study curriculum must be specially tailored to CWD in the class. In addition to this, teachers reject CWD on the basis of issues such as personal hygiene and behavioral problems. This leads to a situation where parents feel hurt and hopeless every time their child is rejected from joining a school.

“When I wanted to send my child to school I had to inform the teacher first, when I said my child was disabled they wouldn’t receive him. I brought documents to the kindergarten and they wouldn’t receive him, they wouldn’t take on my child. They said my child would dribble saliva and cause fights which would make the other parents send their kids elsewhere. I told them my child is clean, he only has problems with his ears, he doesn’t have saliva dribbling out of his mouth! They didn’t believe me, I took him around to so many places, my child is very obedient, he doesn’t cause a ruckass at all!”

- Group with parents of children with hearing impairments

There were cases shared where CWD and their families were teased, slandered and quarreled with by ignorant individuals. On the other hand, for CWD that are currently involved in inclusive education, positive outcomes were shared. Children without disabilities often help their fellow class CWD mates: copy down lessons, helping them up and down staircases, escorting them home.

The current situation is that the more common reluctance of parents towards inclusive education is being reinforced by the negative attitudes and behaviour that are more the norm. This is compounded by a lack of facilities and teaching materials in schools that facilitate inclusivity and the general ignorance

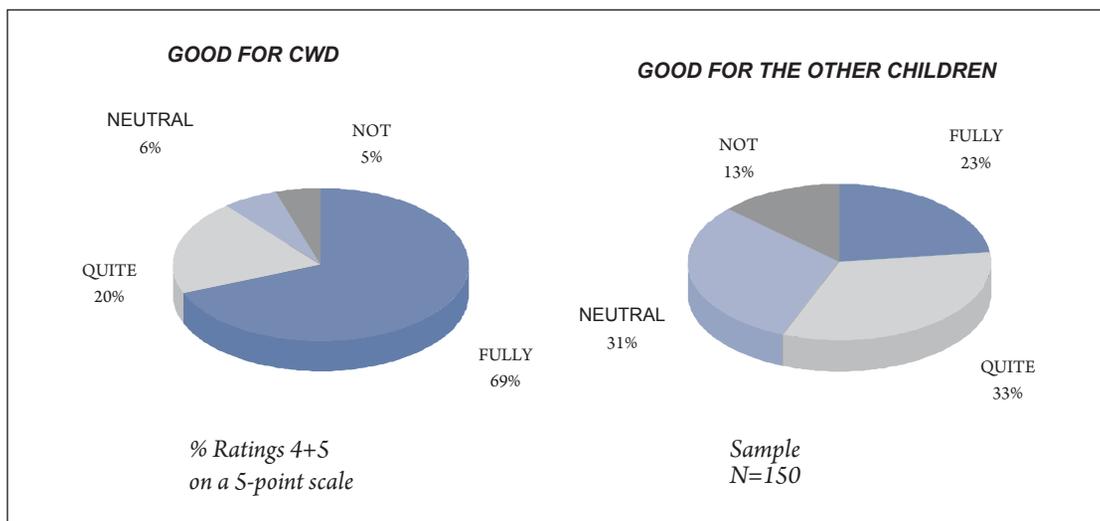
and negativity of a large number of teachers and parents. Parents also expressed much anxiety at sending their child in to inclusive education due to a perception that community services aimed at supporting CWD are still very limited. Stigmatization and discrimination of the community, though considered to be less serious, still exist.

However, there is strong support from government and parties involved, parents always seek for better education for their CWD and parents also seek for more training courses for themselves in order to help their CWD integrate into the community. Thus if more knowledge and positive attitudes could be generated around the benefits of inclusive education for all across the board, and especially with teachers and the broader community, a positive momentum towards inclusive education could be facilitated.

Creating a friendly environment for inclusive education and early intervention as well as longer term vocational education would enable CWD not only to develop their basic self-care skills, but also to enable employment opportunities in their future and a more viable community overall.

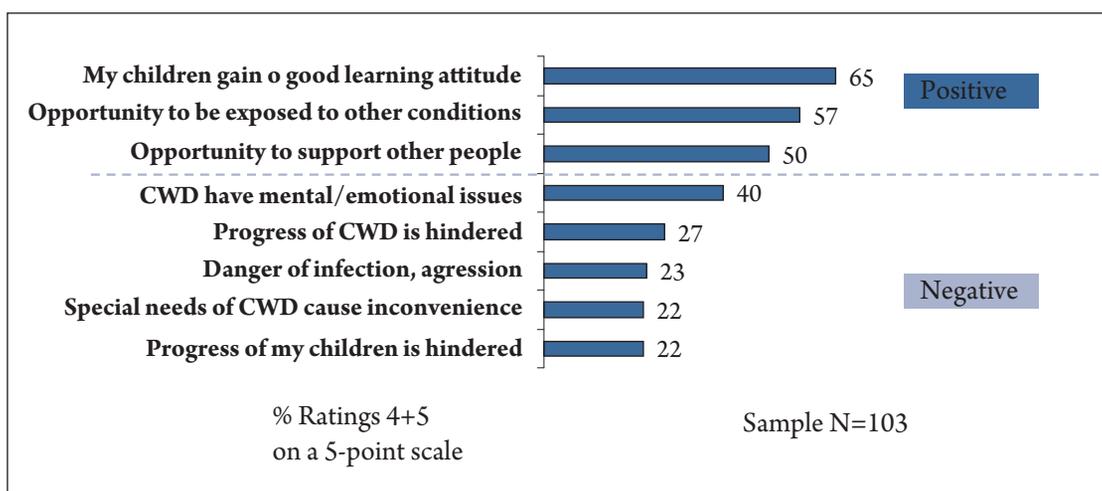
Inclusive education remains a divided issue across the board; both positive and negative attitudes are seen, and again the issue of different disabilities comes to the fore. The Community is quite positive towards inclusive education: 89% agree that it can bring benefits to CWD and 56% that it can be good for the other children. However, there is concern for children with intellectual or behavioral impairment: over 50% of the Community do not want these children to participate in inclusive education. Women are also generally less favorable than men: for behavioral problems, 71% of women do not agree compared to 58% of men.

Figure 4: Inclusive Education



More precisely, when asked to parents of children without disability if they would object to have CWD attend the same school as their children: 65% say YES-they would object for Behavioral problems and 40-50% for Visual/Speech/Hearing and Intellectual. Only Mobility is largely accepted. Parents have positive and negative arguments, as shown hereunder:

Figure 5: Inclusive Education Evaluation



The attitude to inclusive education is related to the broader issue of community comfortability as noted earlier. As noted, over 80% of people feel comfortable when children with physical/visual/hearing/speech impairment live nearby in the community; yet this drops to 65% for intellectual disability and only 30% for behavioral problems.

The perspective of stakeholders

The main mission of MOET and DOET in Da Nang is to encourage inclusive education and to provide specialized programs for CWD with support from NGOs.

MOET is currently working on developing materials and programs which are appropriate for each type of disability and different age groups of children.

DOET coordinates with relevant bodies to encourage CWD's to take part in inclusive education, provides monitoring for individual CWD's development and progress in school (support and scholarship) and organizes programs to promote sharing and supporting between CWD and children without disability ("Vong tay yeu thuong" program).

Main difficulties related to education include:

- Lack of facilities for CWD: specialized equipment, tools such as toys for intellectual development, digital hearing aids, sound-proof rooms, etc.
- Lack of classes in a specialized environment: At present there are only three specialized schools- Tuong Lai, Nguyen Dinh Chieu and Thanh Tam- which are already at over capacity.
- No specific benefits to motivate teachers who teach at inclusive education schools.

2.3. Public facilities and infrastructure to support CWD

The family perspective

CWD's parents expressed their pressing concern about the weak accessibility to means of public transport which is a clear obstacle against integrating their CWD in to the community. There is a general lack of

awareness of the range of infrastructure support that could facilitate CWD inclusion in the community. Public transport is top of mind.

It can be observed that negotiating the traffic and general activity on Viet Nam's streets is a difficult task for those with full sensory capabilities. Motorbikes are the dominant vehicles on the street, alongside a mix of cars, trucks, buses, vans/small work vehicles, bicycles and cyclos. The main form of public transport is buses. Streets are busy and chaotic; there is a lot of small business conducted on pavements (food stalls, etc); pavements are not level nor often in good working condition; likewise bus stops on pavements are also in mixed condition; traffic can come from any direction even on a one-way street, traffic lights are often not observed, and if traffic is particularly congested, motorists can take their motorbikes on to the pavement to try and beat the traffic.

It is a particular issue when parents cannot leave their job to take their children to school and back due to limited resources, no matter what type of disability their children have, for example:

- Concerns raised for those with hearing impairment: children cannot hear the sound and noise in the street; therefore it is much harder for them to avoid vehicles on the street.
- Vision impairment: children cannot see the road and vehicles.
- Mobility disability: children cannot get on/off the bus without any assistance.

Lack of public transport accessibility is clearly having a direct impact on education opportunities for CWD as well as broader societal integration as a whole.

The community perspective

When it comes to problems and issues of CWD and their families as seen by the community, limited access to public transport is rated by 87% at the top scale of difficulties for CWD, whilst limited access to public places comes in second at 80%.

Thus this lack of accessibility is also clearly noted by the community and being so highly apparent to them as an issue, it is likely to gain their engagement and support as a necessary area of support.

The stakeholder perspective

Developing public facilities is rated as a key main improvement area by stakeholders. It is noted that Da Nang receives a relatively large amount of support from Authorities and NGO's, yet it is again pointed out that there is an urgent need for better co-ordination of the programs

The DOC is focusing on constructing means of access and other public construction areas which are friendly to PWD in general. This includes constructing toilets based on guidelines provided by the MOC. The following issues can be observed:

- General lack of facilities for PWD/CWD and low awareness of these facilities.
- A general lack of toilets for PWD.
- Public restrooms for PWD are not frequently used due to poor design that fails to meet their needs.
- Lack of instructions on how to use certain facilities.

With funding from Viet Nam Assistance for the Handicapped (VNAH), several public constructions have been improved in Da Nang to facilitate the accessibility of people with disability. The improvements have mostly been made to create ramps for wheelchair users. They are ramps on the entrance into Da Nang Railway Station; ramps to go up to the stand in Chi Lang Stadium; ramps to get on the pavement on Bach Dang Street and some public toilets.

Across these constructions there are shortcomings to be considered:

- The ramp up to the stand in Chi Lang Stadium is too steep – with such steepness, wheelchair users can barely get up to the stand by themselves.
- In Da Nang Railway Station, the ramp only provides access to the entrance. A person in a wheelchair going from the ticket room in front to the platform will still need assistance.
- It takes 15 minutes to go by motorbike from the centre of Da Nang city to a public toilet equipped with facilities for PWD, as tested by the TNS research team. The guard of the toilet said that it had hardly been used by people with disability. She has a frequent toilet user who is a woman confined to a wheelchair. However, as she observes, this woman has never fully used the specialised aspects of the facility (ramps and grab bars) because she is carried in to the toilet by her husband or brother.
- It is also noted that these constructions largely serve people with physical disability while needs of the visually impaired have not been taken in to account.

3. Communication

3.1. Who to and what to communicate

When it comes to perceptions, the community of Da Nang shows a state of mind that facilitates positive attitudes towards social inclusion of CWD. The statements on perceptions can be divided in to three categories:

1. Respect of the CWD

- Over 90% have a great respect for CWD
- They believe that CWD need respect and support, equal opportunities and that they can live a happy life with a caring environment . They agree that disability can happen to anyone
- They also consider that CWD are protected by Viet Nam and International laws

2. Independence

- 85% think that CWD depend on others most of the time
- But there are positive opinions on independence as well: the CWD can study and make progress, they are able to conduct activities/self care and they can have an independent life with access to social services

3. Society and integration

- 73% think that CWD are treated well by the Viet Nameese society

- Around 60% consider that CWD are a burden for their families and/or for the society; and that they come more from poor families
- 61% believe that CWD can live a normal life

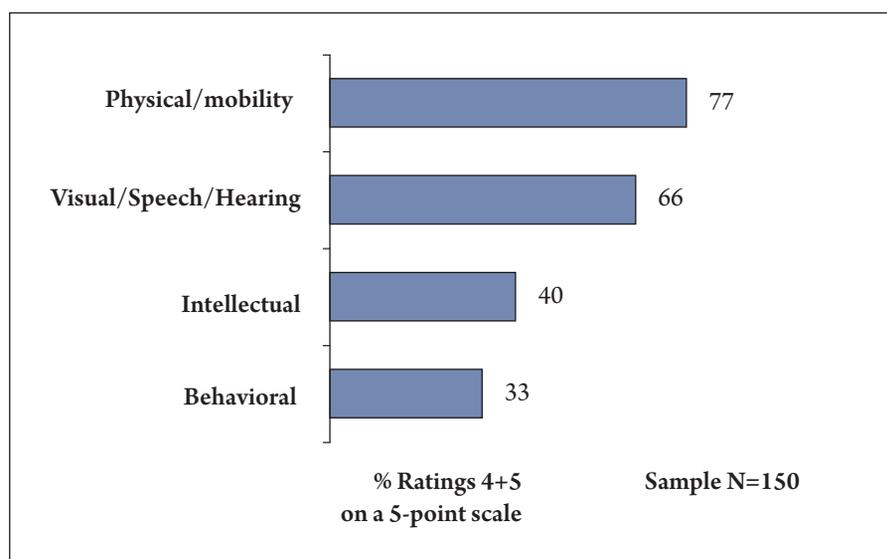
Overall, strong respect for the CWD and confidence that CWD are able to have a good life if the required conditions are met (family care, education, social services), backed up with realism (yes the CWD are more in poor families, depend more on others and present serious challenges to their families). It should be noted that the young generation has a more positive opinion than the older one:

Table 6: CWD can have a normal life

	18-30	31-45	45+
CWD can have a normal life	71%	57%	50%

The perception of the Community varies significantly by type of disability reinforcing this theme across the study:

Figure 6: CWD can participate fully in life



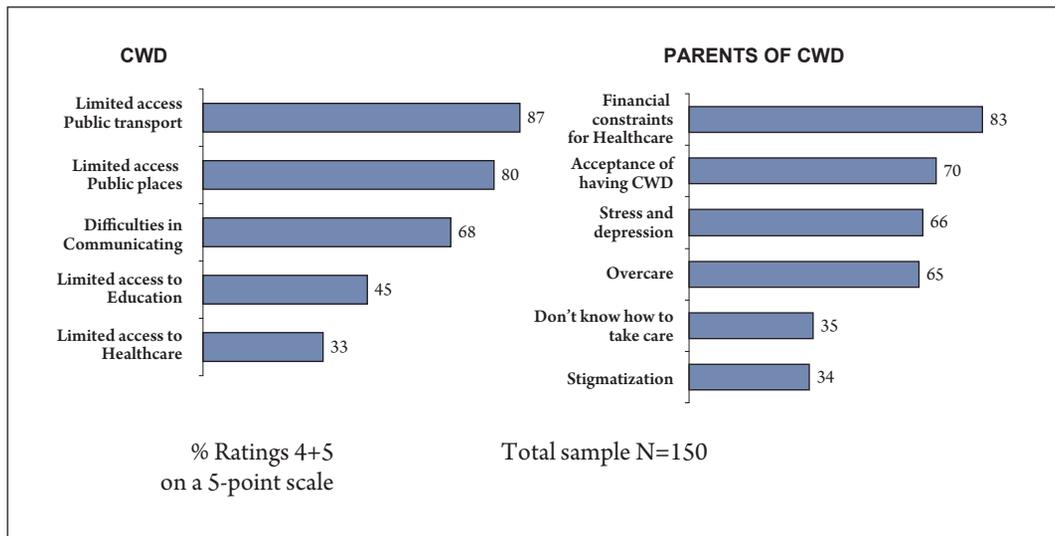
The most common difficulties mentioned by the Community for CWD are:

- Access to public transport and public places - 80% of the Community considers that the local buildings and public facilities are not very accessible for CWD.
- Difficulties in communicating for the children.
- Access to Education and Healthcare.

The main problems mentioned by the Community for the parents of CWD are:

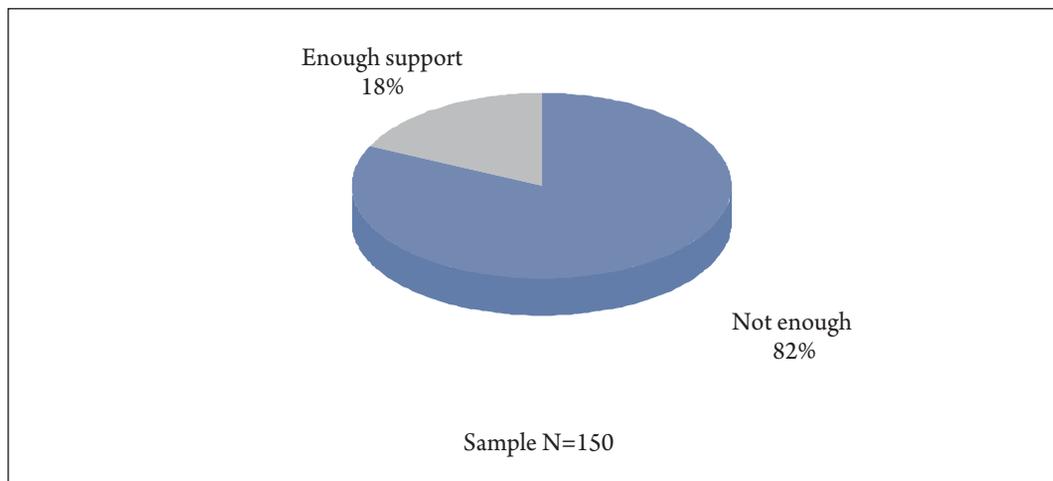
- Financial constraints for Healthcare
- Psychological problems: acceptance of having a CWD, stress/depression, overcare
- Don't know how to care and stigmatization

Figure 7: Difficulties of CWD and their family



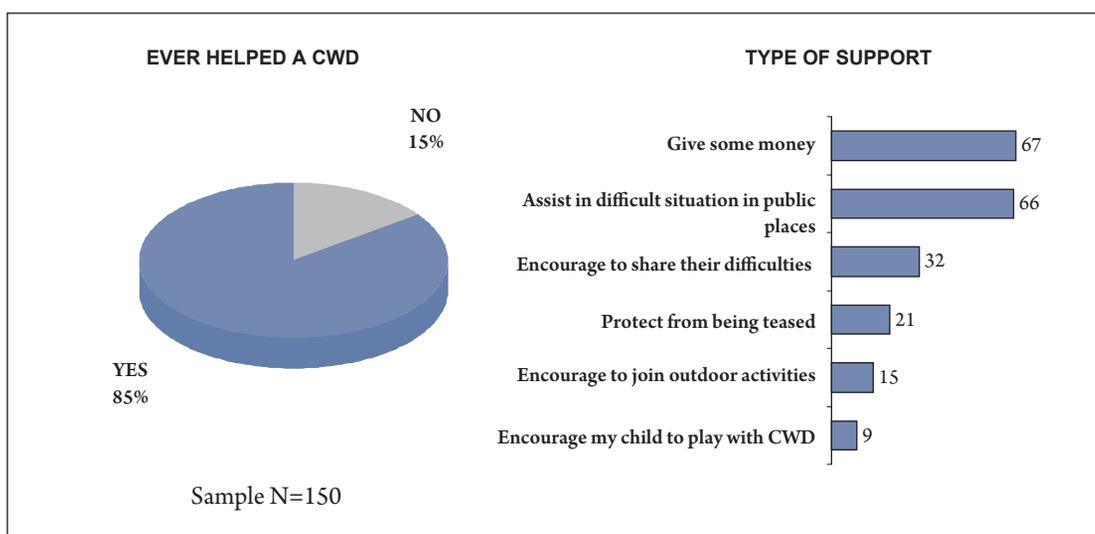
82% of the Community considers that there is not enough support from the Authorities.

Figure 8: Consider of community towards support from Authorities



85% declare that they at least once helped a CWD. However the actions mentioned cannot be considered as a real active support to the CWD in the context of social inclusivity: they gave some money, they helped a child in a public place, they spoke to the child. Main reasons for not helping more is lack of money (68%), the fact that they don't know how to help (59%) and time (37%). 20% cited discrimination of the community against CWD or their own prejudice against CWD.

Figure 9: Support from people to CWD

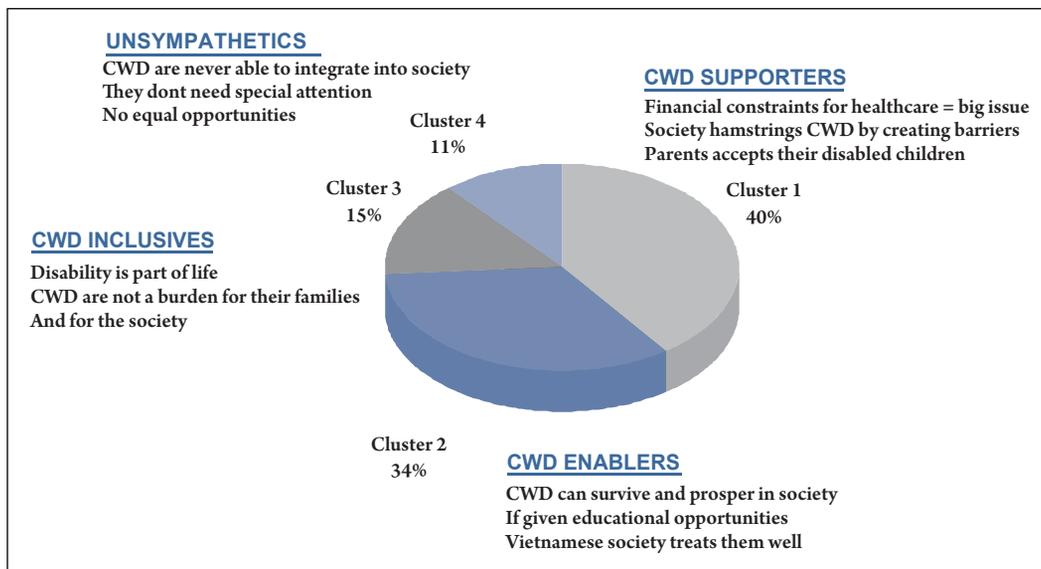


The segmentation analysis results show that based on general perceptions and knowledge towards CWD, 4 target segments can be identified for communication:

CLUSTER	DEFINITION	PERCEPTION
Cluster 1	CWD Supporters (40%)	Parents have no difficulty accepting their children having disabilities They may have financial difficulties in meeting their healthcare needs The problem lies in society's acceptance of CWD, creating barriers
Cluster 2	CWD Enablers (34%)	CWD can survive and prosper in society If given educational opportunities and access to health They are treated well in Viet Nameese society
Cluster 3	CWD Inclusives (15%)	Disability is part of everyday life CWD are not a burden either on their families or on society
Cluster 4	CWD Unsympathetics (11%)	CWD will never be able to integrate into society They don't need special attention – not even access to equal opportunities They can never be independent nor happy

It is very positive to see that the majority belong to the Supporter and Enabler segments, with these groups already having some general knowledge, positive attitudes and practices towards CWD in the community to leverage off and communicate about. Communication programs aimed at these targets will generate the most support and encouragement as a whole to the CWD and their families.

Figure 10: Cluster Definition Pie Chart



89% of the people in Da Nang in total have a positive perception of CWD. They think that CWD should be respected and supported, they believe that they can live a normal life if the following conditions are met: sufficient financial support for healthcare, support from the society (no barriers), educational opportunities.

11% of the people are negative, unsympathetic, thinking that CWD are not able to integrate in to society. Related to the population of Da Nang, this accounts for about 80,000 people.

The two core positive Clusters, CWD Supporters and CSD Enablers, represent 74% of the total population.

3.2. How/means to communicate

Most parents currently look for information through the three schools for children with disability-Thanh Tam School (for children with intellectual disability), Tuong Lai School (for children with hearing impairment) and Nguyen Dinh Chieu School (for children with visual impairment).

TV is felt to be the most interesting source of information by people in Da Nang. Almost all respondents report watching television in their spare time while ¾ of respondents read newspaper or magazines when they are not busy. 30% of respondents surf websites and the percentage of radio listeners is relatively modest, accounting for 14% of the community.

The main times for TV watching are in the evening from 18:00 to 22:00, followed by lunch and afternoon time from 10:00 to 14:00. The channels with the highest number of viewers are Viet Nam Television (VTV3 and VTV1) and Da Nang Television. The program attracting the most viewers is News: as many as 96% of respondents report to watch News frequently. In addition, game shows, soap operas and movies gain a lot of regular viewers (56 to 78%).

Information about CWD is received mainly by television (99% of those who have heard/seen information about CWD; albeit this is predominantly mention of charities in relation to CWD, not

specific information about CWD), followed by newspapers/magazines (63%), local authorities (27%), family/relatives (23%) and friends/colleagues (19%).

The most widespread communication channels for the community are via TV and Print.

3.3. Review of IEC materials

At present, communication materials in Da Nang such as leaflets or brochures to raise people's awareness about the issues of CWD are not widely available. These are summarized in the Appendix, alongside a broader inventory of IEC materials. A few leaflets are published by NGOs (i.e. World Vision in Da Nang, Fred Hollows Foundation, East Meets West) and provided to parents of CWD's mainly at district level (mostly in Hoa Vang District).

For the majority urban areas, NGOs normally directly contact the 3 big schools for CWD's: Thanh Tam school (Mainly for Children with Intellectual Disability), Nguyen Dinh Chieu School (Mainly For Children with Hearing Impairment) and Tuong Lai School (Mainly for Visual Impairment), thus the communication is restricted to these channels which only serve a portion of the CWD segment and their families.

There was very limited awareness of materials or where to get them from our target audience

CONCLUSIONS AND RECOMMENDATIONS

The social model of disability promotes community-based and family-based solutions rather than institutional care. Viet Nam has long applied institutional care, although we can now see a state of transition, where the social approach is progressing in national and local organizations, yet it is still to gain traction that gives it consistency in application and momentum at a support agency, community and most importantly, family and CWD level.

Positively, whilst there is a lot to be done, we see the seeds of change and potential. For example, the perceptions that exist in the majority of the community provide a strong foundation to target with a message of social inclusion for CWD. Where inclusive education exists, we see a positive response on all levels. Across the board, we see consistency in the knowledge, attitudes and perceptions, therefore targeted efforts should promote change across the board.

At a social agency level, clearly better coordination is required to ensure the efforts of all are leveraged towards clear and relevant priority outcomes. Better information for action plans (statistics) will strongly support this. The issue around 'labeling' of disabilities needs to be addressed at both this level, and also through a planned communications strategy that seeks to remove stigmatization around those disability types (especially intellectual disability and multiple disabilities) that are considered different and/or less inclined to social inclusion than others.

Financial support plans, eg. increasing the minimum amount (200,000 VND/month) of support for families are necessary and already in planning as a priority. Consistent and easy access to support needs to be ensured.

With regards to healthcare, better education around healthcare for CWD and their families, as well as healthcare practitioners is essential. This is necessary across the spectrum of prevention, diagnosis,

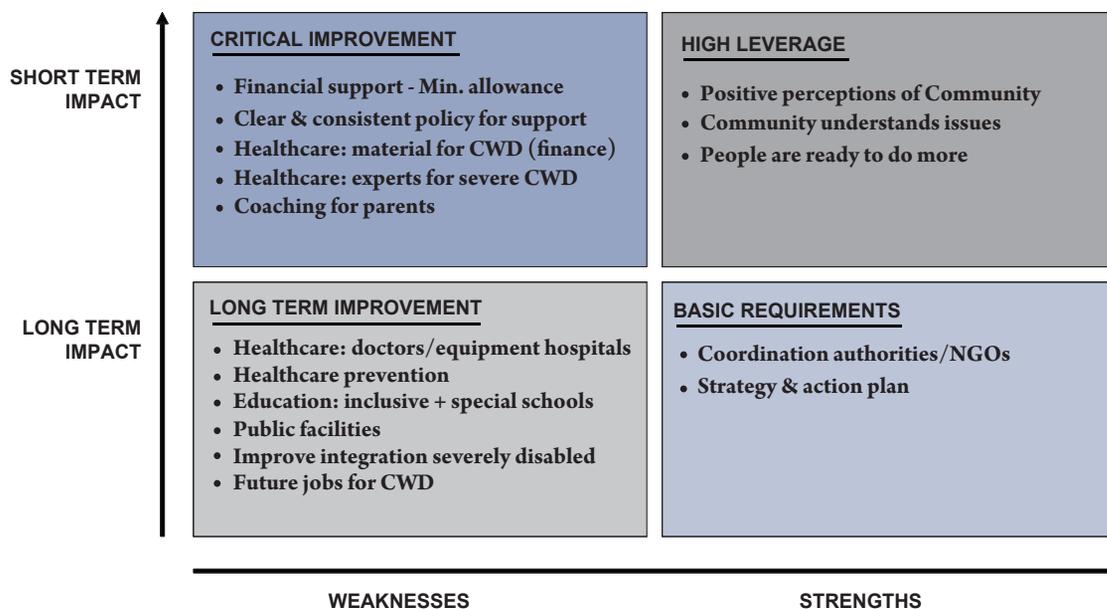
treatment and support. Improved facilities/equipment in hospitals for rehabilitation and early intervention, as well as improved knowledge and skills of health care practitioners on disability. is also required. The access at a local level to education and services across the community needs to be considered, especially in light of the poorer access to what is currently available for those less affluent households.

The issues around inclusive education are similar to healthcare, in the sense that better education and public awareness around inclusive education is necessary for CWD and their families, as well as for teachers/education practitioners who are currently a key barrier. Developing support materials and programs by type of disability, age and general motivation to teachers will support this.

When it comes to infrastructure, accessible public transport for PWD and CWD is not yet available, a key enabling factor for integration in to society, and particularly for inclusive education. Constructed facilities which aim at PWD and CWD need to be sufficient, effectively designed (considering all disability types) and well constructed. Awareness needs to be generated around them and there needs to be clear instructions for usage. This is another key area for better coordination between stakeholders. The importance of a user friendly and accessible environment for PWD and CWD has been recognized and received strong support from many organizations. It is also a clear need for CWD recognized by the broader community. Policies need to be developed in relation to public construction for PWD and CWD, especially in relation to transport to schools, for effective inclusive education, as noted.

The below strategic matrix seeks to summarize these key factors against a dimension of short and long term impact as well as by those which are basic requirements, critical improvement factors and high leverage points.

Figure 11: Long term and short term impact



The positive perceptions of families and the community are key to trigger in a broad and significant communications strategy to help drive change and impact knowledge, attitudes and perceptions at an individual and community level. The majority of the population can embrace the notion that CWD can survive and prosper in society if given educational opportunities and access to health, with

financial support where necessary. They can be supported and treated well in Viet Nameese society. The community can accept disability as a part of everyday life, and this also provides a basis from which to communicate around treating all disabilities the same. If the outtake of a communications message can be the understanding that the problem lies in society's acceptance of CWD, and that it is in fact society creating the barriers, the potential for a significant shift towards a social inclusion model is possible. TV (particularly) and Print are the mainstream means through which to communicate the key messages. A better strategy around information materials, their sufficiency and availability, across both urban and rural areas, is also an obvious need.

APPENDIX 1: ACKNOWLEDGEMENTS

The detailed list of agencies and personnel interviewed is as follows:

Government Organizations and Non – Government Organizations:

- The Ministry of Health (MOH) – Treatment Department, Mr. Tran Quy Tuong, Vice Director of Dept.
- The Ministry of Education and Training (MOET) – Primary School Department, Mr. Tran Dinh Thuan, General Secretary
- The Ministry of Labours, Invalids and Social Affairs (MOLISA) – Bureau of Child Protection and Care, Ms. Nguyen Thi Nga, Chief of the Secretariat
- National Coordinating Committee on Disability of Viet Nam (NCCD) – Mr. Nghiem Xuan Tue, Director
- The Viet Nam Association for Victims of Agent Orange/ Dioxin (VAVA), Mr. Nguyen Trong Nhan, Vice – President
- The Department of Education and Training in Da Nang (DOET), Ms. Huynh Thi Tam Thanh, Vice-Director
- The Department of Health in Da Nang (DOH), Ms. Tran Thi Hoa Ban, Vice-Director
- The Department of Labours, Invalids and Social Affairs (DOLISA), Ms. Nguyen Thi Kim Hong, Vice -Director
- The Department of Construction (DOC), Mr. Tran Dinh Hong, Vice-Director

IEC Materials from:

- Medical Committee Netherlands – Viet Nam (MCNV)
- Hanoi Disabled People Association (DP Hanoi)
- Fred Hollows Foundation (FHF) in Da Nang
- World Vision Viet Nam (WVV) in Da Nang

Project Implementation Staff at TNS:

- Ms Alison Dexter – Research Director, Mrs. Tran Lien Phuong – Group Account Director and Senior Moderator, Mr. Jean-Pierre Depasse, Head of Public & Social Sector; Senior Research Executives: Dam Thu Hang, Le Mai Khanh and Matthew Erickson.
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Advisors:

- The advisors have provided valuable review, comments, and suggestions during the finalization of the document: Ms. Naira Avetisyan, Ms. Nguyen To Tran and Ms. Tran Lien Phuong.

APPENDIX 2: INVENTORY OF IEC MATERIALS

Category	No	Organization/ Author	Publishing house	Title	Publishing Year	Form	Contents
Intel NGO and Vietnamese social organisations' brochures & leaflets: General introduction of activities, including assistance for PWD	1	East Meets West Foundation		Annual Report 2007	2007	Report	Review of EMW activities in 2007
	2	East Meets West Foundation		Reach Viet Nam	2008	Magazine	Review of EMW activities for 20 years in Viet Nam
	3	Fred Hollows Foundation Viet Nam		Fred Hollows Foundation Viet Nam		Brochure	Introduction of Fred Hollows Foundation and its main working area of saving sights in Viet Nam
	4	The Vietnam Association for Victims of Agent Orange (VAVA)		Join hands in appeasing AO/Dioxin connected pains		Leaflet	Introduction of VAVA's functions, tasks and activities in assisting victims of AO
	5	The Vietnam Association for Victims of Agent Orange (VAVA)	Culture and Information Publishing House	Proceedings: the international conference of victims of agent orange	2006		Speeches of delegates at the International Conference of Victims of Agent Orange
Điều lệ và Hướng dẫn	1	MOET, Department of Preschool Education		Guidelines for managing and implementing early interventions and inclusive education for CWD of pre-school level	2007	Book	Definition and process of early intervention for CWD, instructions to implement early intervention
	2	Ha Noi Disabled People Association		Regulations on Organization and Operation	2007	Book	Regulation on Organization and Operation of Hanoi Disabled People Association
	3	National Coordinating Committee on Disability of Vietnam (NCCD)	Labour and Society Publishing House	Biwako millennium framework for actions towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and The Pacific	2006	Book	Summary of 7 priority areas of Biwako Framework: (1) self-help groups of PWDs, (2) women with disabilities, (3) early detection and early intervention, (4) training and vocational education for PWDs, (5) accessible environment for PWDs, (6) access to information and communication and (7) poverty alleviation through capacity building, social security and sustainable live hood programs.

Category	No	Organization/ Author	Publishing house	Title	Publishing Year	Form	Contents
	4	National Coordination Committee on Disability of Vietnam (NCCD)		Convention on the Rights of Persons with Disabilities	2008	Book	Rights of people with disabilities
Books/ Brochure/ Magazine on Disabilities	1	Vu Ngoc Binh	Labour and Society Publishing House	Children with Disabilities and their Rights	2001	Book	Overview of disabilities and situation of PWD in Vietnam
	2	Hanoi Disabled People Association		Hanoi Disabled People Association	2006	Leaflet	Introduction of DP Hanoi and its activities
	3.	Hanoi Disabled People Association		Nang Xuan	2009	Internal Newsletter	Review of activities of Hanoi Disabled People Association, stories of PWD who have overcome their fate.
	4.	CBR Project in Dak Lak		Information for supporting PWD in Dak Lak	2008		Review of CBR activities in Dak Lak, introduction of independent exercise for semi-paralysed people, news on disability screening and job for PWDs
	5	World Vision + USAID	Reference to evaluate children's physical development			Leaflet	The document contains clear descriptions of different stages of children's physical development which are further illustrated by pictures and advice when slow development in the child is noticed
	6	World Vision		How to know that your child have cerebral palsy	2003	Brochure	Definition of cerebral palsy, the most common types of cerebral palsy in the community, symptoms and methods to early detect cerebral palsy in the child. The contents are illustrated with pictures
	7	National Politic Publishing House		Care and Rehabilitation services for children with mobility impairment	2002	Book	Instruction for care for children with mobility impairment caused by cerebral palsy, paralysis or trauma/accidents on how to taking care of those children and do the functional rehabilitation

Category	No	Organization/Author	Publishing house	Title	Publishing Year	Form	Contents
	8	Medical Committee Netherland-Vietnam (MCNV)		Inclusive education for children with hearing impairment (skills for parental education)	2004	Book	Training manual for parents of visually impaired children: necessary awareness for better understanding the children's circumstance and having skills for promoting and stimulating their communication skills.
	9	Medical Committee Netherland-Vietnam (MCNV)		Inclusive education for children with hearing impairments within the Vietnamese context.	2003	Book	Training manual: hearing issues and methodology to stimulating the communication of children with hearing impairment in the community.
	10	Medical Committee Netherland-Vietnam (MCNV)		Some findings of the qualitative report on disability	2008	Book	Some findings of case study on issues related to PWD such as carrier education, needs for injury prevention for children with visual impairment, difficulties faced by young disabled students in Ha Noi
	11		Medical Publishing House	Community based Rehabilitation (a book of reference for PWD and their families)	2006	Book	Situation of PWDs and their families in Vietnam, their benefits, community based rehabilitation and promoting the implementation.
	12		Medical Publishing House	Community based rehabilitation – CBR (manual for rehabilitation staff in community/ collaborator	2006	Book	Situation of PWDs and their families in Vietnam, their benefits, community based rehabilitation and promoting the implementation.

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