Intellectual Disability in Rural Cambodia: Cultural Perceptions & Families' Challenges

Study in Boribor District
Kompong Chhnang Province

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NEW HUMANITY

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Those who are weak have great difficulty finding their place in our society. The image of the ideal human as powerful and capable marginalizes the old, the sick, the less-abled. For me, society must, by definition, be inclusive of the needs and gifts of all its members. How can we lay claim to making an open and friendly society where human rights are respected and fostered when, by the values we teach and foster, we systematically exclude segments of our population?

Jean Vanier, founder of L' Arche

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LIST OF ACRONYMS

ADB	Asian Development Bank
ANC	Antenatal care
CBR	Community-Based Rehabilitation
CCC	Cooperation Committee for Cambodia
CDPO	Cambodian Disabled People’s Organization
CSES	Cambodia Socio-Economic Survey
DAC	Disability Action Council
EMIS	Education Management Information System
MoEYS	Ministry of Education, Youth and Sport
MoSVY	Ministry of Social Affairs, Veterans and Youth Rehabilitation
NGO	Non-governmental organization
NH	New Humanity
PoSVY	Provincial Office of Social Affairs, Veterans and Youth Rehabilitation
RGC	Royal Government of Cambodia
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UXO	Unexploded Ordnance

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This research is just the starting point on studies about intellectual disability in Cambodia. It highlights and encourages the need for discussion on many issues relating to this particular sector of disability. We hope that this research is a new step towards a longer commitment for greater understanding and improved quality of life of children with intellectual disabilities.

EXECUTIVE SUMMARY
(Khmer Version)

ពិការសតិបញ្ញានៅតំបន់ជនបទក្នុងប្រទេសកម្ពុជា:
ការសិក្សាស្រាវជ្រាវ ពីទស្សនៈវប្បធម៌
និងបញ្ហាប្រឈមរបស់គ្រួសារ នៅស្រុកបរិបូណ៌ ខេត្តកំពង់ឆ្នាំង

សេចក្តីសង្ខេបពិសេស

របាយការណ៍នេះបានបង្ហាញពីលទ្ធផលនៃការសិក្សាស្រាវជ្រាវអំពីគម្រោងមួយដែលបានអនុវត្តពីខែធ្នូ ឆ្នាំ២០០៩ ដល់ខែមេសា ឆ្នាំ២០១១ ក្រោមការឧបត្ថម្ភរបស់អង្គការមនុស្សលោកថ្មីកម្ពុជា ដែលជាអង្គការក្រៅរដ្ឋាភិបាលអន្តរជាតិមួយជួយកុមារពិការសតិបញ្ញា និងគ្រួសាររបស់ពួកគេ។ ការសិក្សានេះបានធ្វើឡើងក្នុងស្រុកបរិបូណ៌ ខេត្តកំពង់ឆ្នាំងដោយប្រើប្រាស់ទាំងវិធីសាស្ត្រស្រាវជ្រាវបែបបរិមាណវិស័យ រួមមានការស្ទង់មតិ និងវិធីសាស្ត្រស្រាវជ្រាវបែបគុណវិស័យ រួមមានការសម្ភាសន៍ស៊ីជម្រៅ ជាមួយគ្រួសាររបស់កុមារពិការសតិបញ្ញា។

ជំហានដំបូង ក្រុមការងារបានធ្វើការសិក្សាលើឯកសារដែលពាក់ព័ន្ធនឹងផ្នែកពិការភាពជាពិសេសផ្តោតលើពិការសតិបញ្ញាក្នុងប្រទេសកម្ពុជា និងប្រទេសជិតខាង។ ជំហានទីពីរ ក្រុមការងារបានចុះប្រមូលទិន្នន័យបន្ទាប់បន្សំ អំពីអត្រាពិការភាព និងចំនួនប្រជាជន ពីអជ្ញាធរមូលដ្ឋាន និងអង្គការពាក់ព័ន្ធនានាក្នុងស្រុកបរិបូរណ៌។ ជំហានទីបី ការស្ទង់មតិដោយប្រើប្រាស់កម្រងសំណួរបានធ្វើឡើងជាមួយ៧២គ្រួសារ ដែលក្នុងនោះមានគ្រួសារដែលបានទទួលផលពីអង្គការមនុស្សលោកថ្មីចំនួន៣០គ្រួសារ និងគ្រួសារដែលមិនបានទទួលផលពីអង្គការមនុស្សលោកថ្មីចំនួន៤២គ្រួសារ។ ជំហានទីបួន ក្រុមការងារបានធ្វើការសម្ភាសន៍យ៉ាងស៊ីជម្រៅជាមួយគ្រួសារចំនួន៨ ក្នុងចំណោមគ្រួសារទាំងអស់ខាងលើដើម្បីយកធ្វើជាករណីសិក្សា ក្នុងនោះមាន៤គ្រួសារដែលទទួលផលពីអង្គការមនុស្សលោកថ្មី។ លើសពីនេះទៅទៀត ក្រុមការងារបានធ្វើការសម្ភាសន៍ជាមួយអជ្ញាធរមូលដ្ឋានចំនួន១៣នាក់ គ្រូបង្រៀននៅសាលារដ្ឋចំនួន១០នាក់ និង

គ្រូបង្រៀនកុមារមានតម្រូវការពិសេសដែលកំពុងបម្រើការនៅអង្គការមនុស្សលោកថ្មី ចំនួន១៣នាក់ទៀត។ ជំហានទីប្រាំ ក្រុមការងារបានវិភាគលើទិន្នន័យបែបបរិមាណវិស័យដោយប្រើកម្មវិធី SPSS ហើយវិភាគទិន្នន័យបែបគុណវិស័យ ដោយប្រើកូដ និងបង្កើតចំណាត់ថ្នាក់ជាក្រុម ដើម្បីកំណត់នូវបែបផែនព័ត៌មានដែលទទួលបាន។

គោលបំណងនៃការសិក្សាស្រាវជ្រាវនេះគឺ ដើម្បីធ្វើការវិភាគស្ថានភាពផ្នែកពិការសតិបញ្ញានៅតំបន់ជនបទក្នុងប្រទេសកម្ពុជា តាមរយៈការពិនិត្យលើការរស់នៅរបស់កុមារពិការសតិបញ្ញា និងគ្រួសាររបស់ពួកគេ ព្រមទាំងស្វែងយល់ពីផ្នត់គំនិត និងជំនឿស្តីពីពិការភាពជាពិសេសពិការសតិបញ្ញា។ ការសិក្សាស្រាវជ្រាវនេះបង្ហាញផងដែរនូវស្ថានភាពរស់នៅ និងបញ្ហាប្រឈម របស់គ្រួសារកុមារពិការសតិបញ្ញា និងគ្រូបង្រៀនកុមារមានតម្រូវ ការពិសេសក្នុងការធ្វើការជាមួយកុមារពិការសតិបញ្ញា ។

ការសិក្សាស្រាវជ្រាវនេះព្យាយាមសិក្សាផងដែរអំពីអាកប្បកិរិយា និងទង្វើរបស់គ្រួសារ និងសហគមន៍ (ដូចជា បងប្អូនបង្កើត គ្រូបង្រៀន មិត្តរួមថ្នាក់ និងអ្នកជិតខាង) ដើម្បីស្វែងយល់ថាតើពួកគេយល់ឃើញយ៉ាងណាអំពីការរើសអើងចំពោះកុមារពិការសតិបញ្ញា។ ទន្ទឹមនឹងនេះ លទ្ធផលនៃការស្វែងយល់ពីផ្នត់គំនិតបែបបុរាណ និងផ្នត់គំនិតបច្ចុប្បន្នស្តីពីពិការភាព និងមូលហេតុនៃពិការភាព ក៏បានបញ្ចូលក្នុងការស្រាវជ្រាវនេះផងដែរ។

ជាចុងបញ្ចប់ ការសិក្សានេះបានព្យាយាមកំណត់រកភាពខុសគ្នារវាងគ្រួសារដែលបានទទួលផល និងគ្រួសារដែលមិនទទួលផលពីអង្គការមនុស្សលោកថ្មី ដោយផ្តាតទៅលើការយល់ដឹងរបស់ពួកគេអំពីពិការភាព ការឆ្លើយតបរបស់ពួកគេទៅនឹងពិការភាព និងថាតើសេវាដែលទទួលបានមានឥទ្ធិពលលើជីវភាពប្រចាំថ្ងៃរបស់ពួកគេយ៉ាងណាដែរ។

របកគំហើញពីទស្សនៈវប្បធម៌នៃពិការសតិបញ្ញា

ភាសានៃពិការភាព

ពាក្យជាច្រើនសម្រាប់ពិពណ៌នាពីពិការកាយសម្បទា ត្រូវបានចាប់ផ្តើមដោយពាក្យ «ពិការ» ដែលមានន័យដើមថា "ការផ្លាស់ប្តូរ" នៃលក្ខខណ្ឌ/ឋានៈ។ ប៉ុន្តែពាក្យដែលប្រើសម្រាប់ពិពណ៌នាជនពិការសតិបញ្ញាម្នាក់ហាក់ដូចជាមានអត្ថន័យអវិជ្ជមានជាច្រើន។ ទោះបីជានាពេលបច្ចុប្បន្ននេះ ភាសាដែលបានប្រើក្នុងការពិពណ៌នាអំពីពិការសតិបញ្ញា បានផ្លាស់ប្តូរទៅជាពាក្យស្រាលៗ ដូចជា ពិការខួរក្បាល មានបញ្ហាខាងសតិបញ្ញា កំសោយបញ្ញា ឬបញ្ញាអន់ ក៏ដោយ ក៏ការផ្លាស់ប្តូរទាំងនេះកើតមានក្នុងវិស័យដែលទទួលការអប់រំតែប៉ុណ្ណោះ។ ពាក្យ «epilepsy» មានន័យថាឆ្កួតជ្រូក និងមានន័យថាស្កន្ធម្តាយដើម «វិញ្ញាណអាក្រក់ពីម្តាយមុន»។ ពាក្យនេះក៏ត្រូវបានគេប្រើប្រាស់ចំពោះជម្ងឺស្វិតសរសៃប្រសាទ និងជម្ងឺរលាកស្រោមខួរផងដែរ។ គំនិតបែបសាសនានៃការប្រើប្រាស់ពាក្យ ឆ្កួតជ្រូក អាចមកពីមូលហេតុដែលឪពុកម្តាយជឿថា ជម្ងឺឆ្កួតជ្រូក មានទំនាក់ទំនងជាមួយនឹងវិញ្ញាណអាក្រក់ ហើយចំពោះការព្យាបាលជំងឺប្រភេទនេះ ពួកគាត់ជឿថាមានតែទៅរកគ្រូខ្មែរទេ។

ជំនឿសាសនា និងផ្នត់គំនិតអំពីពិការភាព

តាមការវិភាគទៅលើរឿងនិទាន យើងបានរកឃើញថា កាលពីដើមឡើយជនពិការត្រូវបានគេស្គាល់ ប៉ុន្តែត្រូវបានគេដាក់ឲ្យនៅឋានៈទាបបំផុតក្នុងសង្គម។ ផ្ទុយទៅវិញ ក្នុងករណីខ្លះ ជនពិការក៏ត្រូវបានគេចាត់ទុកថាជាផ្នែកសំខាន់នៃសង្គមផងដែរ ពីព្រោះពួកគេអាចរំលឹកយើងពីភាពមិនមាំទាំរបស់មនុស្ស។ រឿងផ្សេងៗទៀតបញ្ជាក់ពី «ការទទួលស្គាល់» ជនពិការនៅក្នុងសង្គមកម្ពុជា ប៉ុន្តែអត្ថន័យនៅចុងបញ្ចប់នៃរឿងទាំងនេះមានការរំពឹងទុកថានឹងទទួលបានការជាសះស្បើយទាំងស្រុង ដោយបានប្តូររូបរាងទៅជាមនុស្សថ្មីម្នាក់ដ៏ប្រសើរ។ បច្ចុប្បន្ននេះ ផ្នត់គំនិតអាចត្រូវបានបែងចែកជាពីរគឺ ផ្នត់គំនិតមួយដែលបញ្ជាក់ពីការឆ្លើយតបអវិជ្ជមាន និងមួយទៀតបង្កើតការឆ្លើយតបវិជ្ជមានចំពោះពិការសតិបញ្ញា។

រឿងព្រេងនិទានបុរាណ និងរឿងរ៉ាវជីវិតរបស់ជនពិការកាលពីយូរលង់មកហើយ បាន បង្ហាញយ៉ាងច្បាស់ពីការករកើតរចនាសម្ព័ន្ធថានានុក្រមនៅក្នុងទស្សនៈលោកីយកម្ពុជា ដែលមានមាត្រដ្ឋានតម្លៃមួយ និងមានការទទួលស្គាល់ពីសង្គម យោងទៅតាមប្រភេទនៃពិការភាព។ នៅក្នុងឋានានុក្រមនេះ ជនពិការដៃជើង និងមនុស្សគថ្លង់ មានថានៈសង្គមខ្ពស់ជាងអ្នកពិការសតិបញ្ញា និងមនុស្សឡប់សតិ ដោយសារអ្នកទាំងនេះត្រូវបានគេយល់ឃើញថាមានសមត្ថភាពក្នុងការ «ជំនះ» ពិការភាពរបស់ពួកគេ។ យ៉ាងណាមិញ អ្នកពិការសតិបញ្ញានៅតែត្រូវបានបដិសេធមិនទទួលយកដោយពេញលេញពីសង្គម ព្រមទាំងត្រូវបានបដិសេធមិនទទួលស្គាល់ថាជាពលរដ្ឋពេញលេញដោយសារតែពួកគេ «មិនអាចរៀបអាពាហ៍ពិពាហ៍បាន» នេះជាឧទាហរណ៍នៃសូចនាករសំខាន់មួយសំរាប់វាស់វែងពីសមត្ថភាពរបស់ជនពិការក្នុងការបំពេញទំនួលខុសត្រូវនៅក្នុងសង្គមកម្ពុជា។ ទោះជាជនពិការដៃជើងត្រូវបានបង្ហាញថាអាចមានឱកាសលើកតម្កើងក្នុងសង្គមកម្ពុជានាពេលបច្ចុប្បន្នក៏ដោយ ក៏ពួកគេនៅតែត្រូវបានរើសអើង និងមានឱកាសទទួលបានការងារតិចតួច។

របកគំហើញពីបញ្ហាប្រឈមដែលគ្រួសារបានជួបប្រទះ

ស្ថានភាពសេដ្ឋកិច្ចសង្គមរបស់គ្រួសារ

ការសិក្សាបានរកឃើញថា គ្រួសារភាគច្រើនដែលមានកូនបួននាក់ ឬច្រើនជាងនេះ បាន រៀនយ៉ាងហោចណាស់ចប់បឋមសិក្សា និងជាប្រជាកសិករ។ ពួកគេរស់នៅក្នុងផ្ទះធ្វើពីសម្ភារៈធម្មជាតិ (ឈើ ស្លឹកត្នោត ឬស្បូវ ឬស្សី) ហើយប្រើប្រាស់កង់ ដែលក្នុងចំណោមពួកគេមានអ្នកខ្លះគ្មានទាំងមធ្យោបាយធ្វើដំណើរផង។ ពួកគេគ្មានប្រភពចំណូលបិតថេរទេ និងមានការលំបាកក្នុងការផ្គត់ផ្គង់តម្រូវការប្រចាំថ្ងៃ ដោយសារគេពឹងទៅលើការងារតាមរដូវកាលដើម្បីរកប្រាក់ចំណូល។ ទោះជាគ្រួសារភាគច្រើនជាគ្រួសារក្រីក្រដែលចិញ្ចឹមជីវិតដោយសារប្រាក់ចំណូលតិចជាង ១០០០០រៀលក្នុងមួយថ្ងៃ (ប្រហែល ២.៥០ ដុល្លាអាមេរិក) ក៏ដោយ ក៏គ្រួសារដែលទទួលផលទំនងជាមានប្រភពចំណូលបិតថេរជាងគ្រួសារដែលមិនទទួលផល។

យើងអាចសន្និដ្ឋានបានថា គ្រួសារដែលទទួលផលពីអង្គការមនុស្សលោកថ្មីអាចរកប្រាក់ចំណូលបានច្រើនជាង ពីព្រោះពួកគេមានការចល័តការងារបានច្រើន មានន័យថាពួកគេមិន

ចាំបាច់ផ្តល់ការថែទាំជាប្រចាំដល់កូនពិការរបស់គេឡើយ ដូច្នេះក្នុងកំឡុងពេលនេះពួកគេអាចធ្វើការងាររកប្រាក់បាន។

គ្រួសារទទួលបានការគាំពារមុន និងក្រោយពេលសម្រាលកូន

គ្រួសារភាគច្រើនព្យាយាមទទួលការគាំពារមុនពេលសម្រាល (ANC)។ គ្រួសារក្រៅពីនេះមិនបានទទួលការគាំពារមុនពេលសម្រាលទេ ដោយសារតែពួកគេមិនមានថវិការគ្រប់គ្រាន់ ឬមិនយល់ពីតម្រូវការនៃការគាំពារមុនពេលសម្រាល។ ចំពោះគ្រួសារដែលទទួលការគាំពារមុនពេលសម្រាលគឺបានទទួលការពិនិត្យមុនពេលសម្រាលម្តងក្នុងរយៈពេលតិចជាងមួយត្រីមាស។ គ្រួសារស្ទើរតែទាំងអស់បានទៅមន្ទីរពេទ្យ ឬមន្ទីរពហុព្យាបាលដើម្បីទទួលការគាំពារមុនពេលសម្រាល និងមួយចំនួនតូចបានទៅរកគ្រូខ្មែរ ឬឆ្មបបុរាណ។ ប៉ុន្តែទោះបីជាមានគ្រួសារមួយចំនួនសម្រាលកូននៅមន្ទីរពេទ្យ ឬមន្ទីរពហុព្យាបាលក៏ដោយ ក៏មានគ្រួសារភាគច្រើនបានសម្រាលកូននៅផ្ទះផងដែរ។ ម្តាយៗទាំងអស់សុទ្ធតែស្វែងរកការគាំពារក្រោយពេលសម្រាល ដោយក្នុងនោះម្តាយភាគច្រើនបានទទួលការគាំពារពីគ្រូខ្មែរ។

យើងអាចសន្និដ្ឋានបានថា ពេលដែលម្តាយទាំងអស់ហាក់ដូចជាព្យាយាមទទួលការគាំពារក្រោយពេលសម្រាលជាជាងមុនពេលសម្រាល ពួកគេហាក់ដូចជាជ្រើសរើសរបៀបគាំពារ និងព្យាបាលតាមបែបបុរាណជាជាងសេវាទំនើបនៅតាមមន្ទីរពេទ្យ ឬមន្ទីរពហុព្យាបាលជាពិសេសការគាំពារក្នុងពេលសម្រាលកូន និងក្រោយពេលសម្រាល។

ផ្នត់គំនិតឪពុកម្តាយពីមូលហេតុនៃពិការសតិបញ្ញារបស់កូន

ឪពុកម្តាយកំណត់បានមូលហេតុនៃពិការសតិបញ្ញារបស់កូនគាត់ ដោយផ្អែកទៅលើទាំងផ្នែកវេជ្ជសាស្ត្រ និងវប្បធម៌។ ឪពុកម្តាយបានបង្ហាញពីកម្រិតយល់ដឹងខ្ពស់នៃមូលហេតុផ្នែកវេជ្ជសាស្ត្រ ដោយឪពុកម្តាយភាគច្រើនយល់ថាកង្វះអាហាររូបត្ថម្ភរបស់ម្តាយ ឬកុមារ គឺជាមូលហេតុ ហើយមួយចំនួនទៀតយល់ថាការគ្រុនក្តៅខ្លាំងជាប្រចាំគឺជាមូលហេតុ។ បើតាមក្រុមទីពីរ (មូលហេតុផ្អែកលើវប្បធម៌) គឺឪពុកម្តាយភាគច្រើនបកស្រាយស្ថានភាពកូនរបស់ពួកគាត់តាម

គោលការណ៍កម្មផលនៃពុទ្ធសាសនា និងការចាប់ជាតិជាថ្មី ដោយយល់ថាទង្វើដែលបានធ្វើពីជាតិមុនកំណត់នូវលទ្ធផល និងគុណភាពជីវិតរបស់បុគ្គលម្នាក់នៅក្នុងជាតិនេះ។

យើងអាចសន្និដ្ឋានបានថា ឪពុកម្តាយជឿថាពិការសតិបញ្ញាបណ្តាលពីមូលហេតុដែលផ្អែកលើវេជ្ជសាស្ត្រ និងវប្បធម៌ ហើយមូលហេតុទាំងពីរខាងលើនេះផ្អែកលើជំនឿបុរាណ និងជំនឿពុទ្ធសាសនាពីបាបកម្ម និងការចាប់ជាតិ ដែលបណ្តាលឲ្យមានការកើតមកខុសពីធម្មតា។

ការរកឃើញទាន់ពេល

ទោះបីជាឪពុកម្តាយទាំងអស់បានសំគាល់ឃើញពីការកើតឡើងនូវរោគសញ្ញាជាក់លាក់មួយចំនួនដូចជា គ្រុនក្តៅខ្លាំងជាប្រចាំ ឬការប្រកាច់ក៏ដោយ ឪពុកម្តាយភាគច្រើនមិនដឹងថារោគសញ្ញាទាំងនេះជាសញ្ញាគ្រោះថ្នាក់ដែលអាចបង្កឲ្យមានការលូតលាស់យឺត ឬខ្សោយសតិបញ្ញានោះទេ។ គ្រូបង្រៀននៅសាលារដ្ឋ អជ្ញាធរមូលដ្ឋានទាំងអស់ និងគ្រូមត្តេយ្យរបស់អង្គការមនុស្សលោកថ្មីដែលបានចូលរួមក្នុងការសម្ភាសន៍ មិនបានយល់ថារោគសញ្ញាទាំងនេះជាសញ្ញាគ្រោះថ្នាក់នៃការខ្សោយសតិបញ្ញាឡើយ។ គ្រូបង្រៀនកុមារមានតម្រូវការពិសេសនៅមណ្ឌលស្តារលទ្ធភាពពលកម្មសហគមន៍របស់អង្គការមនុស្សលោកថ្មីមានការយល់ដឹងច្បាស់ជាងគេអំពីការការពារ ការកំណត់សញ្ញាណពិការភាព និងការព្យាបាល ព្រោះពួកគេបានទទួលវគ្គបណ្តុះបណ្តាលកម្រិតខ្ពស់អំពីប្រធានបទទាំងនេះ។ ឪពុកម្តាយភាគច្រើនបានសំគាល់ពីភាពខុសប្លែកនៃការលូតលាស់របស់កូនគាត់នៅពេលមានអាយុ១ឆ្នាំ។ ករណីភាគច្រើន ឪពុកម្តាយ និងបងប្អូនជិតស្និទ្ធគឺជាមនុស្សដំបូងដែលបានកត់សំគាល់ឃើញភាពខុសប្លែកគ្នាទាំងនេះ។ ឪពុកម្តាយស្ទើរតែ ៧៥% បានព្យាយាមស្វែងរកសេវាសុខភាព ទាំងបែបសម័យទំនើប និងបែបបុរាណ។ ៨៥% ក្នុងចំណោមពួកគាត់បានទៅមន្ទីរពេទ្យរដ្ឋ ឬមន្ទីរពហុព្យាបាលឯកជន និង ១១% បានទៅរកគ្រូខ្មែរជាមុនសិន។ ឪពុកម្តាយជាងពាក់កណ្តាលបាននិយាយថា ពេទ្យជំនាញដែលពួកគាត់បានទៅរក មិនអាចដឹងពីស្ថានភាពពិការភាពរបស់កូនគាត់ឡើយ។ ក្នុងចំណោមការព្យាបាលដែលពួកគេទទួលបាន គឺភាគច្រើន (៧២%) បានទទួលវេជ្ជបញ្ជាសំរាប់ទិញថ្នាំ។ មានតែកុមារមួយចំនួនតូចប៉ុណ្ណោះបានទទួលការព្យាបាល ឬត្រូវបានបញ្ជូនទៅរកការប្រឹក្សាបន្ថែមទៀត។

មានឪពុកម្តាយ៩៩% បានព្យាយាមស្វែងរកការព្យាបាលជាលើកទីពីរ ហើយមាន៥០% បានទៅរកគ្រូខ្មែរ។ ឪពុកម្តាយមានឆន្ទៈក្នុងការចំណាយលុយព្យាបាលកូនរបស់ពួកគាត់ប្រសិនបើមានឱកាសជាសះស្បើយ ឬមានលក្ខខណ្ឌសុខភាពល្អប្រសើរជាងមុននោះ។ ឪពុកម្តាយដែលជឿថាមូលហេតុនៃពិការភាពរបស់កូនគាត់ទាក់ទងនឹងជំនឿវប្បធម៌នោះ ភាគច្រើនទៅរកគ្រូខ្មែរឲ្យជួយ។ ទោះជាជំនឿកម្មផលបង្កឲ្យមានការបណ្តោយទៅតាមវាសនានៅកម្រិតណាមួយក៏ដោយ ក៏នៅតែមានគ្រួសារមួយចំនួនដែលបណ្តោយតាមស្ថានការ ហាក់បីដូចជាមានភាពអសកម្ម និងមិនស្ទុះស្ទារកសេវាកម្មអ្វីឡើយ ប៉ុន្តែចំពោះគ្រួសារមួយចំនួនដែលទទួលស្គាល់នូវស្ថានការ ហាក់ដូចជាសម្របសម្រួល និងរិះរកវិធីដើម្បីឆ្លើយតបទៅនឹងតម្រូវការកូនរបស់គាត់។ បើយើងប្រៀបធៀបក្រុមទាំងពីរ អ្នកដែលទទួលផលពីអង្គការមនុស្សលោកថ្មីព្យាយាមស្វែងរកការព្យាបាលជាលើកទីពីរ ច្រើនជាងអ្នកមិនទទួលផលពីអង្គការ។ ក្រៅពីនេះទៀត អ្នកដែលមិនទទួលផលពីអង្គការព្យាយាមស្វែងរកការព្យាបាលពីគ្រូខ្មែរនៅលើកទីពីរច្រើនជាងអ្នកទទួលផលពីអង្គការ។

យើងអាចសន្និដ្ឋានថា ការបណ្តុះបណ្តាលដែលអ្នកពាក់ព័ន្ធបានទទួលកាន់តែច្រើន ពួកគេកាន់តែយល់ពីការការពារ ការកំណត់រកពិការភាព និងការព្យាបាល។ នៅពេលដែលឪពុកម្តាយព្យាយាមស្វែងរកការព្យាបាលតាមបែបទំនើបនៅលើកដំបូងនោះ ពួកគាត់ហាក់ដូចជាព្យាយាមស្វែងរកការព្យាបាលតាមវិធីបុរាណនៅពេលពួកគាត់រកជំនួយជាលើកទីពីរ។ ឪពុកម្តាយដែលជឿថាមូលហេតុនៃពិការសតិបញ្ញារបស់កូនគាត់ទាក់ទងនឹងជំនឿវប្បធម៌នោះគឺភាគច្រើនព្យាយាមរកជំនួយពីគ្រូខ្មែរ។

ការទទួលបានការអប់រំ

កុមារជាងពាក់កណ្តាលទទួលបានសេវាអប់រំ ដែលស្ទើរតែពាក់កណ្តាលនៃពួកគេទៅរៀននៅសាលារដ្ឋ។ ភាគច្រើននៃកុមារទាំងនេះមានដោនស៊ីនដ្រូមកម្រិតស្រាល។ គ្រួសារដែលមិនបានបញ្ជូនកូនទៅសាលាគឺដោយសារហេតុផលផ្សេងៗ រួមមានផ្លូវពីផ្ទះទៅសាលាមានចម្ងាយឆ្ងាយ ខ្វះខាតធនធានហិរញ្ញវត្ថុ និងមានជំនឿថាកូនគាត់នឹងមិនអាចទទួលបានប្រយោជន៍អ្វីពីការអប់រំនោះទេ។ កុមារពិការសតិបញ្ញា ដែលត្រូវបានគេគិតថាអាចទទួល

ផលប្រយោជន៍ពីការអប់រំតិចតួចនោះ ហាក់ដូចជាទទួលបានការអប់រំតិចជាងកុមារដែលមានបញ្ហាកាយសម្បទា។ លើសពីនេះ ដោយសារតែកង្វះខាតសម្ភារៈ និងការសម្របសម្រួល ធ្វើឲ្យគ្រូបង្រៀនមិនចង់ទទួលពួកគេឲ្យចូលរៀនឡើយ។ ការមិនឲ្យតម្លៃដល់គ្រូបង្រៀនកុមារពិការសតិបញ្ញា គឺជាប្រការមួយដែលធ្វើឲ្យការងារនេះមិនមានការចាប់អារម្មណ៍ច្រើនពីមនុស្សឯទៀតជាហេតុនាំឲ្យមានការកាត់បន្ថយក្រុមមនុស្សដែលយើងរំពឹងថាអាចមានសមត្ថភាពក្លាយជាគ្រូបង្រៀនកុមារពិការ។ បើយើងប្រៀបធៀប រវាងក្រុមទាំងពីរ គឺក្រុមដែលទទួលផលពីអង្គការមនុស្សលោកថ្មី មានការពេញចិត្តនឹងគុណភាពនៃសេវាអប់រំដែលពួកគេបានទទួលច្រើនជាងក្រុមមិនបានទទួលផលពីអង្គការ។ ចំនុចនេះប្រហែលមកពីការពិតដែលអង្គការមនុស្សលោកថ្មីផ្ដល់នូវការបង្រៀនរយៈពេលប្រាំបីម៉ោងក្នុងមួយថ្ងៃ (បើប្រៀបធៀបនឹងការបង្រៀនរយៈពេលបីម៉ោងនៅសាលារដ្ឋ) មានផ្ដល់អាហារពេលព្រឹកនិងថ្ងៃត្រង់ មានគ្រូដែលនទទួលបានការបណ្ដុះបណ្ដាល មានកម្មវិធីសិក្សានិងសម្ភារៈសមស្រប មានការអប់រំជាបុគ្គលនិងមានផែនការស្ដារលទ្ធភាពពលកម្ម មានផ្ដល់មធ្យោបាយធ្វើដំណើរទៅមកដោយរ៉ឺម៉កកង់បី ពីផ្ទះទៅសាលានិងមានការប្រឹក្សាជាមួយគ្រួសារជាបុគ្គលនិងជាក្រុម ក៏ដូចជាការបណ្ដុះបណ្ដាលផ្នែកកសិកម្មដើម្បីឲ្យមានអាហារចម្រុះនិងបង្កើនកម្រិតអាហារូបត្ថម្ភរបស់កុមារផងដែរ។ គ្រួសារដែលមិនបានទទួលផលភាគច្រើនបានរកជំនួយពីមិត្តភក្តិ ឬអ្នកជិតខាងអោយជួយយកកូនទៅសាលារៀន។ កុមារពិការសតិបញ្ញាទៅសាលារៀនតិចជាងកុមារពិការកាយសម្បទា ដោយសារតែផ្នត់គំនិតទូទៅយល់ថាពួកគេនឹងមិនទទួលបានប្រយោជន៍ពីការអប់រំ ហើយគ្រូបង្រៀនក៏មិនបានទទួលវគ្គបណ្ដុះបណ្ដាលជំនាញពិសេសគ្រប់គ្រាន់ និងមិនមានឆន្ទៈក្នុងការទទួលយកពួកគេដែរ។ ឪពុកម្ដាយនៅតែពេញចិត្តសេវាជាច្រើនដែលពួកគាត់បានទទួលពីអង្គការមនុស្សលោកថ្មីជាង ទោះបីជាកុមារដោនស៊ីនដ្រូមកម្រិតស្រាលមួយចំនួនបានទទួលការអប់រំនៅសាលារដ្ឋក៏ដោយ។

យើងអាចសន្និដ្ឋានថា ពេលដែលគ្រូកាន់តែច្រើនទទួលបានវគ្គបណ្ដុះបណ្ដាលជំនាញពិសេស ហើយឪពុកម្ដាយអាចទទួលបានសេវាជំនួយបន្ថែមទៀតពីលើសេវាអប់រំនោះ នឹងមានកុមារពិការសតិបញ្ញាកាន់តែច្រើនត្រូវបានបញ្ជូនទៅសាលារៀន។

បញ្ហាប្រឈមក្នុងការចិញ្ចឹមកូនពិការសតិបញ្ញា

ក្នុងចំណោមគ្រួសារដែលបានស្ទង់មតិនិយាយថា បញ្ហាប្រឈមមុខចម្បងរបស់ពួកគាត់ (៣៩%) គឺជាការទទួលខុសត្រូវក្នុងការមើលថែកូនដែលពិការសតិបញ្ញាជាប្រចាំ។ បញ្ហាប្រឈមមួយទៀតគឺតម្រូវការជំនួយដើម្បីជួយកូនពួកគាត់ (ជំនាញ ឬជំនួយបច្ចេកទេស) ដែលជាពិសេសពាក់ព័ន្ធនឹងការលំបាកក្នុងការប្រាស្រ័យទាក់ទងជាមួយកូនរបស់ខ្លួន។ បញ្ហាប្រឈមផ្សេងទៀតពាក់ព័ន្ធនឹងបញ្ហាលុយកាក់ ដោយសារតែចំណាយលើការថែទាំសុខភាព។ ឪពុកម្ដាយប្រហែលជាពាក់កណ្ដាលបាននិយាយថា ការមើលថែកូនរបស់គាត់គឺ «គ្រាន់តែជាផ្នែកមួយនៃជីវិតរបស់ពួកគាត់ប៉ុណ្ណោះ»។ តួនាទីយេនឌ័រដែលបានកំណត់កាលពីពេលមុនប្រហែលជាអាចពន្យល់បញ្ហានេះបាន ដោយហេតុថាម្ដាយត្រូវមានតួនាទីជាអ្នកថែទាំ និងទស្សនៈពុទ្ធសាសនាពីការទទួលស្គាល់ការពិត។ ប៉ុន្តែមានគ្រួសារ៤៥%បាននិយាយថាតម្រូវការថែទាំ និងការប្រឹងប្រែងជាប្រចាំមានការហត់នឿយ និងត្រូវការការលះបង់ដ៏ធំធេងពីសមាជិកគ្រួសារ។ គ្រួសារជាច្រើនបានបង្ហាញពីភាពហត់នឿយទាំងកម្លាំងកាយ និងចិត្ត។

បើប្រៀបធៀបក្រុមទាំងពីរ អ្នកមិនទទួលផលពីអង្គការបានឲ្យចំណាត់ថ្នាក់ចំពោះការចំណាយលើការថែទាំសុខភាពថាជាបញ្ហាចម្បងជាងអ្នកទទួលផលពីអង្គការ។ ហេតុផលនេះអាចមកពីកុមារដែលទទួលផលបានទទួលការគាំទ្រផ្នែកសុខភាពពីអង្គការមនុស្សលោកថ្មី។ ម្យ៉ាងវិញទៀត អ្នកទទួលផលបានឲ្យចំណាត់ថ្នាក់ចំពោះ តម្រូវការជំនួយផ្នែកជំនាញ និងការពិបាកទំនាក់ទំនងជាមួយកូនរបស់ពួកគាត់ជាបញ្ហាចម្បងជាង។ នេះមានន័យថា នៅពេលដែលគ្រួសារសង្កេតឃើញពីអត្ថប្រយោជន៍នៃសេវាដែលកូនបានទទួលនោះ ពួកគាត់កាន់តែយល់ពីលទ្ធភាពក្នុងការអភិវឌ្ឍ និងតម្រូវការជំនាញពិសេសដើម្បីជួយកូនគាត់ឲ្យបានកាន់តែប្រសើរ។ ការផ្ដល់ការថែទាំជាប្រចាំដល់កូនពិការសតិបញ្ញាមានផលប៉ះពាល់យ៉ាងខ្លាំងដល់ក្រុមគ្រួសារ ពីព្រោះវាមិនមែនត្រឹមតែរារាំងដល់ឱកាសរកប្រាក់ចំណូលបន្ថែមឪពុកម្ដាយប៉ុណ្ណោះទេ តែថែមទាំងមានផលប៉ះពាល់ទាំងផ្លូវកាយ និងផ្លូវចិត្តដល់សមាជិកគ្រួសារទៀតផង។ អ្នកទទួលផលជួបប្រទះបទពិសោធន៍នេះតិចតួចជាងអ្នកដែលមិនទទួល ផលដោយសារតែពួកគាត់បានទទួលសេវាអប់រំ និងសេវាសុខភាព ដែលបានកាត់បន្ថយបន្ទុកនៃការថែទាំ និងចំណាយលើផ្នែកសុខភាព។ យ៉ាងណាមិញ ពេលដែលអ្នកទទួលផលចាប់ផ្ដើមសង្កេតឃើញពី

ផលប្រយោជន៍នៃសេវាទាំងនេះ ពួកគេមានការរំពឹងទុកកាន់តែច្បាស់លាស់ពីតម្រូវការជំនាញពិសេសបន្ថែមទៀតដើម្បីឆ្លើយតបទៅនឹងតម្រូវការកូនរបស់ខ្លួន។

ការគាំទ្រដែលបានផ្តល់ឲ្យគ្រួសារ

ទោះបីជាអ្នកទទួលផលមានដល់ទៅជិតពាក់កណ្តាលនៃសំណាកគំរូទាំងអស់ក៏ដោយ ក៏មានតែ៣៧% ប៉ុណ្ណោះដែលសារភាពថាបានទទួលការឧបត្ថម្ភមួយចំនួន នេះប្រហែលជាពួកគេគិតថាអាចទទួលបានជំនួយបន្ថែមទៀត ឬក៏ខ្លាចថាជំនួយដែលពួកគាត់កំពុងទទួលបានអាចបញ្ឈប់ទៅវិញ។ គ្រួសារភាគច្រើនបាននិយាយថាពួកគាត់ទទួលជំនួយពីអង្គការផ្សេងៗដូចជាអង្គការមនុស្សលោកថ្មី និងអង្គការកម្ពុជាត្រាស្ត រីឯមួយចំនួនតូចនិយាយថាពួកគេទទួលបានការឧបត្ថម្ភពីស្ថាប័នសុខភាពសាធារណៈ អ្នកជិតខាង និងសហគមន៍។ អង្គការក្រៅរដ្ឋាភិបាលជាប្រភពជំនួយដ៏សំខាន់ចំពោះគ្រួសារដែលមានកូនពិការសតិបញ្ញា។ ចំនួនសេវាកម្មរបស់អង្គការក្រៅរដ្ឋាភិបាលមានកំណត់ បានសេចក្តីថាគ្រួសារភាគច្រើននឹងមិនទទួលបានសេវាសម្រាប់កូនពួកគាត់ទេ ជាពិសេសនៅតំបន់ជនបទ។

អារម្មណ៍ឪពុកម្តាយចំពោះស្ថានភាពកូន

ឪពុកម្តាយមានអារម្មណ៍វិជ្ជមាន និងអវិជ្ជមានពីស្ថានភាពកូនរបស់គាត់។ ឪពុកម្តាយភាគច្រើនដែលមានអារម្មណ៍វិជ្ជមានចំពោះកូន បាននិយាយថាពួកគាត់មានការអាណិតអាសូរ ហើយអ្នកខ្លះទៀតសម្តែងនូវសេចក្តីសង្ឃឹម។ ឪពុកម្តាយមួយចំនួនដែលមានអារម្មណ៍អវិជ្ជមានបាននិយាយថាពួកគាត់មានការអស់សង្ឃឹម។ នៅពេលដែលពិការភាពមានសភាពធ្ងន់ធ្ងរ ឪពុកម្តាយមានការខូចចិត្ត ដែលការខូចចិត្តនេះអាចបន្ធូរបន្ថយបានដោយការអត់ទ្រាំ និងជំនឿថានេះគឺមកពីបាបកម្មរបស់កូន ដែលនៅបរិបទបស្ចឹមប្រទេសបកស្រាយថាជាយថាកម្ម។ យ៉ាងណាមិញ យើងបានរកឃើញនៅក្នុងការសិក្សានេះថា ឪពុកម្តាយទាំងនេះមានការឆ្លើយតបពីរផ្សេងគ្នាចំពោះពិការភាពកូនរបស់ខ្លួន។ ការឆ្លើយតបមួយមានការទទួលយកនូវឥរិយាបទ ទ្រាំតាមកម្ម។ ឥរិយាបទនេះបានធ្វើឲ្យសមាជិកគ្រួសារមានភាពអសកម្មចំពោះកូន និងមិនផ្តល់ឱកាសឲ្យកូនបង្កើននូវលក្ខខណ្ឌរស់នៅ ឬក៏គុណភាពជីវិតឡើយ។ ការឆ្លើយតបមួយទៀតមាន

ឥរិយាបទទទួលយកយ៉ាងសកម្ម ដែលធ្វើឲ្យឪពុកម្ដាយទទួលស្គាល់នូវស្ថានភាព (ឧទាហរណ៍ពិការភាពមិនអាចព្យាបាលបាន និងមិនអាចបាត់ទៅវិញទេ) និងរិះរកវិធីដែលពួកគាត់អាចធ្វើបានដើម្បីសុខមាលភាពរបស់កូន។

បើប្រៀបធៀបក្រុមទាំងពីរ អ្នកទទួលផលបានសម្ដែងការអាណិតអាសូរ និងសេចក្ដីសង្ឃឹមច្រើនជាងអ្នកមិនទទួលផល។ ឪពុកម្ដាយដែលទទួលផល មានការយល់ដឹងកាន់តែប្រសើរអំពីស្ថានភាពកូនរបស់ខ្លួន និងបានសម្គាល់ឃើញពីផលប្រយោជន៍នៃសេវាទាំងនេះចំពោះកូនរបស់ពួកគាត់។ ពួកគាត់ចាប់ផ្ដើមមានសុទិដ្ឋិនិយម និងមានសង្ឃឹមកាន់តែខ្លាំងពីអនាគតកូនរបស់ខ្លួន។ តែផ្ទុយទៅវិញ ចំពោះឪពុកម្ដាយដែលមិនបានទទួលផលហាក់ដូចជាមានការអស់សង្ឃឹម និងចុះចាញ់។

បទពិសោធន៍ឪពុកម្ដាយជាមួយនឹងការរើសអើង

ឪពុកម្ដាយមិនបានដឹងពីទង្វើរបស់ពួកគេចំពោះកូនខ្លួនថាជាការរើសអើងនោះទេ ប៉ុន្តែបែរជាយល់ថាជាការបង្ហាញពីភាពសប្បាយពេញចិត្ត និងការគោរពទៅវិញ ដែលទង្វើទាំងនេះអាចរាប់បញ្ចូលទាំងការដាក់ងារមិនល្អ ឬចាក់សោរកូននៅក្នុងផ្ទះពេលមានភ្ញៀវជាអ្នកធ្វើការមកលេងផ្ទះ។ ឪពុកម្ដាយមិនបានមើលឃើញពីទង្វើផ្សេងៗរបស់សមាជិកសហគមន៍ ថាជាការរើសអើងឡើយ ទោះបីជាពួកគាត់ទទួលស្គាល់ថាកូនគាត់មានតម្លៃទាបនៅក្នុងសង្គមក៏ដោយ ទង្វើទាំងនេះមានដូចជា គេមិនទៅលេងផ្ទះរបស់ពួកគាត់ ដោយសារតែគាត់មានកូនពិការសតិបញ្ញា ការផ្ដល់យោបល់ថាឲ្យសម្លាប់ចោល ឬមិនឲ្យយកកូនទៅវត្ត ឬទៅបុណ្យនៅក្នុងភូមិជាដើម។ អ្នកធ្វើការជំនាញនៅអង្គការមនុស្សលោកថ្មីដែលបានទទួលវគ្គបណ្ដុះបណ្ដាលអំពីការស្វែងយល់នូវឥរិយាបទមិនរើសអើង បានមើលឃើញទង្វើរបស់ឪពុកម្ដាយ និងសមាជិកសហគមន៍ថាជាការរើសអើង និងយល់ឃើញថាជំនឿដែលថាម្ដាយជាអ្នកមានកំហុសជាអាកប្បកិរិយារបស់សមាជិកសហគមន៍។

ទស្សនៈនៃការរើសអើងភាគច្រើន គឺអាស្រ័យទៅលើរបៀបដែលបុគ្គលបកស្រាយនូវបទពិសោធន៍របស់ពួកគេ។ សមាជិកសហគមន៍បានរើសអើងកុមារ និងគ្រួសារ ដោយមិនឲ្យកុមារចូលរួមពិធីបុណ្យនានាក្នុងភូមិ និងការដាក់កំហុសទៅលើម្ដាយពីស្ថានភាពកូនរបស់គេ។

ការព្រួយបារម្ភ និងការរំពឹងទុករបស់ឪពុកម្តាយពីអនាគតកូន

ការព្រួយបារម្ភធំជាងគេដែលឪពុកម្តាយគ្រប់រូបបានកំណត់នោះ គឺជាការភ័យព្រួយពីអ្វីដែលអាចកើតមាន ប្រសិនបើពួកគាត់ស្លាប់ចោលកូន។ ការរំពឹងទុកត្រូវបានផ្សារភ្ជាប់ទៅនឹងការអប់រំ ការស្វែងរកការព្យាបាល និងក្តីសង្ឃឹមថាកូនអាចម្ចាស់ការក្នុងការមើលថែខ្លួនឯង។ តាមការចោទសួរថា តើពួកគាត់រំពឹងថានឹងសម្រេចលទ្ធផលទាំងនេះដូចម្តេច? ឪពុកម្តាយភាគច្រើនបាននិយាយថាពួកគាត់ផ្ញើក្តីសង្ឃឹម និងទំនុកចិត្តលើអង្គការទាំងស្រុង តែក៏មានឪពុកម្តាយមួយចំនួនតូចគិតថាការថែទាំពីសហាគមន៍ និងសមាជិកគ្រួសារដែលបានផ្តល់ឲ្យអាចនឹងមានប្រសិទ្ធភាព។

បើប្រៀបធៀបក្រុមទាំងពីរនេះ ក្រុមគ្រួសារដែលបានទទួលផល មានការព្រួយបារម្ភពីអនាគតកូនតិចជាងគ្រួសារដែលមិនបានទទួលផល។ ក្រុមគ្រួសារដែលបានទទួលផលបានមើលឃើញតម្រូវការសេវាអប់រំ និងសេវាស្តារលទ្ធភាពពលកម្ម ដើម្បីជួយកូនរបស់គាត់ឲ្យមានការរីកចម្រើនច្រើនជាងគ្រួសារដែលមិនទទួលផល។ ឪពុកម្តាយដែលបានទទួលសេវា និងការគាំទ្រ បានចាប់ផ្តើមមើលឃើញពីការរីកចំរើន និងលូតលាស់របស់កូនក្នុងការអភិវឌ្ឍជំនាញ។ ពេលឪពុកម្តាយបានឃើញពីការអភិវឌ្ឍរបស់កូន ពួកគាត់កាន់តែមានសង្ឃឹមចំពោះអនាគតកូន។ ពួកគាត់ថែមទាំងមានកង្វល់តិចជាងមុន ក្នុងការស្វែងរកនូវការព្យាបាល ហើយហាក់ដូចជាទទួលយកនូវស្ថានភាពរបស់កូន និងខំស្វែងរកវិធីផ្សេងៗដើម្បីឆ្លើយតបទៅនឹងតម្រូវការរបស់ពួកគេ។

បញ្ហាប្រឈមចំពោះបុគ្គលិកស្តារលទ្ធភាពសហាគមន៍របស់អង្គការមនុស្សលោកថ្មី

បញ្ហាប្រឈមធំបំផុតគឺការបង្រៀនអ្នកទទួលផល និងក្រុមគ្រួសាររបស់គេ អំពីអនាម័យ និងការថែទាំសុខភាព ព្រមទាំងសារៈសំខាន់របស់វា។ កុមារពិការសតិបញ្ញាភាគច្រើនរស់នៅក្នុងលក្ខខណ្ឌដែលមិនស្អាត និងគ្មានអនាម័យបំផុត។ ពួកគេរស់នៅផ្ទាល់ដី ដោយមិនទទួលបានទឹកស្អាត។ ម្តាយខ្លះដែលជានិច្ចកាលជាអ្នកទទួលបន្ទុកទាំងនេះ គ្មានកម្លាំងគ្រប់គ្រាន់ដើម្បីលើកដាក់កូនប្រុស ឬស្រីពិការធំៗឲ្យប្រើប្រាស់បង្គន់បានទេ។ សុខភាព និងលក្ខខណ្ឌអាហាររូបត្ថម្ភរបស់កុមារក៏ជាការព្រួយបារម្ភមួយរបស់បុគ្គលិកអង្គការដែរ។ គ្រូបង្រៀនក៏បាន

សម្តែងការព្រួយបារម្ភអំពីការរីករាលដាលនៃ ការប្រើប្រាស់ថ្នាំដោយខ្លួនឯងរបស់ឪពុកម្តាយដូចជាពេលខ្លះមានការប្រើថ្នាំខុស ព្រោះចង់ធ្វើយ៉ាងណាឲ្យតែកូនគាត់បានធូរស្រាលខ្លះ។

គ្រូបង្រៀនកុមារមានតម្រូវការពិសេសក៏បានរកឃើញផងដែរថា ការងារថៃទាំកុមារ និងការធ្វើឲ្យឪពុកម្តាយយល់ពីសារៈសំខាន់ក្នុងការបញ្ជូនកូនទៅសាលារៀនទៀងទាត់ ក៏ដូចជាការជំរុញឲ្យឪពុកម្តាយចូលរួមសកម្មភាពបណ្តុះបណ្តាល ពិតជាមានការលំបាកខ្លាំងណាស់។ គ្រូបង្រៀនកុមារមានតម្រូវការពិសេសទាំងអស់បានបញ្ចប់ការសិក្សារបស់ខ្លួននៅសាលារដ្ឋចន្លោះថ្នាក់ទី៩ និងថ្នាក់ទី១២ ហើយពួកគាត់មានភាពងាយស្រួលក្នុងការរៀនដោយការធ្វើត្រាប់តាម (ដូចជាដោយការមើល និងការធ្វើ) ដែលពាក់ព័ន្ធនឹងការអនុវត្តជាជាងការអាននូវទ្រឹស្តី ឬវិធីសាស្ត្រតាមសៀវភៅ។ យ៉ាងណាមិញ ដោយចំនួនគ្រូបង្រៀនកុមារមានតម្រូវការពិសេស ដែលបានទទួល ការបណ្តុះបណ្តាលនៅប្រទេសកម្ពុជាមានកំណត់ ហើយការចំណាយក្នុងការជួលទីប្រឹក្សាពីខាងក្រៅ ឬទីប្រឹក្សាបរទេសមកបណ្តុះបណ្តាលមានតំលៃខ្ពស់ ជាហេតុនាំឲ្យឱកាសនៃការអនុវត្តផ្ទាល់ទាំងនេះមានតិចតួចណាស់ មានរយៈពេលខ្លីពេក ហើយតែងតែមិនមានចីរភាព។ គ្រូមិនអាចបំពេញបន្ថែមចំណេះដឹងរបស់ខ្លួន តាមរយៈការអាននូវឯកសារដ៏ច្រើនលើសលុបស្តីពីពិការភាព ដែលបានបង្កើតឡើងដោយអង្គការក្រៅរដ្ឋាភិបាល និងស្ថាប័នអន្តរជាតិជាច្រើន នោះទេ បើទោះជាឯកសារទាំងនោះអាចរកបានងាយស្រួលក៏ដោយ ព្រោះតែឯកសារទាំងនោះភាគច្រើន សរសេរជាភាសាអង់គ្លេស។

ការព្រួយបារម្ភភាគច្រើនដែលបានលើកឡើងដោយគ្រូបង្រៀននោះ វាមិនស្របគ្នាជាមួយការបារម្ភរបស់ឪពុកម្តាយទេ។ មាតាបិតាបារម្ភពីអនាគតកូនរបស់គាត់ ចំណែកឯគ្រូព្រួយបារម្ភពីបច្ចុប្បន្នភាពរបស់ក្មេង ដោយយល់ឃើញថាលក្ខខណ្ឌនៃការរស់នៅទាបអាចរារាំងនូវលទ្ធភាពក្នុងពេលអនាគត។ ម្យ៉ាងវិញទៀត បើសិនជាការផ្តល់ដំបូន្មានដល់មាតាបិតាដោយមិនបានផ្តល់នូវជម្រើស និងយោបល់ច្បាស់លាស់ទេ នោះវាគ្មានប្រសិទ្ធភាពក្នុងការផ្លាស់ប្តូរទង្វើ និងឥរិយាបទរបស់មាតាបិតាចំពោះការរក្សាអនាម័យឡើយ។

អនុសាសន៍

យើងមានជាបញ្ជីអនុសាសន៍ សម្រាប់ការអនុវត្តតាមរយៈការសហការរួមគ្នារវាងអ្នកអនុវត្តដែលពាក់ព័ន្ធទាំងអស់ ដូចជា ជនពិការសតិបញ្ញា ក្រុមគ្រួសារ រដ្ឋាភិបាល និង ស្ថាប័ន/អង្គការផ្សេងៗ។

បង្កើតប្រព័ន្ធព័ត៌មានស្ដីពីពិការសតិបញ្ញា

សមាជិកក្រុមគ្រួសារកុមារខ្សោយសតិបញ្ញាគួរតែទទួលបានព័ត៌មាន និងការបណ្ដុះបណ្ដាលបន្ថែមទៀតពីរបៀបថែទាំ និងរបៀបដោះស្រាយស្ថានភាពរបស់កុមារ។ កាលណាឪពុកម្ដាយបានទទួលព័ត៌មាន និងទទួលការណែនាំកាន់តែច្រើនពីពិការសតិបញ្ញារបស់កូនពួកគាត់មានអារម្មណ៍ថាកាន់តែបានចូលរួម និងកាន់តែចង់ធ្វើអ្វីមួយដើម្បីជួយកូនរបស់ខ្លួន។ ប្រធានបទនានាសម្រាប់ការបណ្ដុះបណ្ដាលអាចជា៖

- ពិការភាពជាអ្វី (ពិការសតិបញ្ញា) និងការជាប់ទាក់ទងនៃផ្នែកសុខភាព និងសង្គម។
- ប្រភេទនៃពិការសតិបញ្ញា ជាពិសេសប្រភេទដែលមានច្រើនក្នុងបរិបទកម្ពុជា និងអាការពិសេសរបស់វា
- ការការពារ និងការស្វែងរកទាន់ពេលវេលា ក៏ដូចជាការព្យាបាលដែលអាចធ្វើបាន ដូច្នេះឪពុកម្ដាយអាចចូលរួមក្នុងការព្យាបាលដោយចលនា និងការព្យាបាលដោយឡែកទៀតអាស្រ័យទៅតាមប្រភេទនៃពិការភាព។
- មូលដ្ឋាននៃអនាម័យ ទឹកស្អាត និងអនាម័យខ្លួនប្រាណ
- ផលប៉ះពាល់អវិជ្ជមាននៃការប្រើប្រាស់ថ្នាំដោយខ្លួនឯង
- ជម្រើសក្នុងការអប់រំដែលអាចមាន និងឱកាសការងារសមស្របនៅពេលបន្ទាប់ទៀត
- បញ្ញត្តិក្នុងច្បាប់ និងគោលនយោបាយនានាដែលទាក់ទងនឹងសិទ្ធិបុគ្គល និងសិទ្ធិមាតាបិតា និងការផ្ដល់សេវា។

ការផ្សព្វផ្សាយ និងការបណ្ដុះបណ្ដាលពីប្រធានបទទាំងអស់នេះ គួរតែធ្វើដល់គ្រប់អ្នកពាក់ព័ន្ធទាំងអស់ រួមទាំងមាតាបិតា លោកគ្រូ អ្នកគ្រូ វេជ្ជបណ្ឌិត ដើម្បីឆ្ពោះទៅរកការដាក់បញ្ចូលកុមារពិការ ដូចដែលបានបញ្ញត្តិក្នុងច្បាប់ស្ដីពីការការពារ និងលើកកម្ពស់សិទ្ធិជនពិការ

ប្រកបដោយជោគជ័យ។ វិធីសាស្ត្រឆ្លើយតបតាមបែបវប្បធម៌គួរតែត្រូវបានពិចារណា ក្នុងការផ្សព្វផ្សាយ និងការបណ្តុះបណ្តាល។ ការផ្លាស់ប្តូរភាសាអំពីពិការភាពអាចជាជំហានដំបូងក្នុងការផ្លាស់ប្តូរផ្នត់គំនិតអវិជ្ជមានចំពោះជនពិការសតិបញ្ញា។ ដូច្នេះពាក្យប្រើក្នុងការហៅជនពិការសតិបញ្ញាដែលមានអត្ថន័យអវិជ្ជមានតិចតួច ឬគ្មានទាល់តែសោះ គួរត្រូវបានបង្រៀន និងផ្សព្វផ្សាយ។ អ្នកផ្តល់សេវាកម្ម មិនគួរព្យាយាមកែប្រែជំនឿបុរាណរបស់ប្រជាជនពីមូលហេតុនៃការពិការសតិបញ្ញានោះទេ ផ្ទុយទៅវិញគួរតែបង្ហាញពីឥរិយាបទគោរព អមជាមួយយុទ្ធនាការផ្សព្វផ្សាយព័ត៌មានប្រកបដោយប្រសិទ្ធភាព។

បណ្តុះជំនាញដើម្បីធ្វើការជាមួយជនពិការសតិបញ្ញាប្រកបដោយប្រសិទ្ធភាព

កម្មវិធី និងវគ្គបណ្តុះបណ្តាលជាច្រើនទៀតគួរតែត្រូវបានបង្កើត និងផ្តល់ជូនគ្រូបង្រៀនដោយណែនាំពួកគាត់អំពីកម្មវិធីសិក្សាពិសេស និងបច្ចេកទេសពីរបៀបបង្រៀនកុមារពិការសតិបញ្ញា។ ដូច្នេះ កាលណាគ្រូបង្រៀនទទួលបានវគ្គបណ្តុះបណ្តាលពិសេសកាន់តែច្រើន ឪពុកម្តាយទទួលបានសេវាអប់រំ និងសេវាជំនួយកាន់តែច្រើន នោះកុមារពិការសតិបញ្ញាកាន់តែច្រើននឹងទៅសាលារៀន។ បុគ្គលិកសុខភាពត្រូវការទទួលវគ្គបណ្តុះបណ្តាលពិសេសពីការថែទាំមាតុភាព និងពិការសតិបញ្ញាផងដែរ។ ការប្រើប្រាស់សេវាសុខភាពសាធារណៈរបស់ឪពុកម្តាយគួរតែត្រូវបានលើកទឹកចិត្ត ដោយការបង្កើតយុទ្ធសាស្ត្ររួមមួយរវាងឪពុកម្តាយ និងបុគ្គលិកសុខភាព។ កុមារពិការសតិបញ្ញាម្នាក់ៗគួរតែទទួលបានការព្យាបាលជាពិសេស។ ឪពុកម្តាយ គ្រួសារ អ្នកថែទាំពិសេស ត្រូវតែទទួលបានលើកទឹកចិត្តឲ្យបង្កើននូវគុណភាពជីវិតរបស់កុមារពិការសតិបញ្ញា។ អ្នកផ្តល់សេវា មាតាបិតា បងប្អូន និងសហគមន៍ជាទូទៅត្រូវរៀនទទួលស្គាល់ និងតស៊ូមតិប្រឆាំងជាមួយសកម្មភាពរើសអើងទាំងឡាយទាំងក្នុង និងក្រៅសហគមន៍របស់ខ្លួន។ ព្រោះតែឪពុកម្តាយដែលមានកូនពិការសតិបញ្ញាជាច្រើននៅតែបន្តទទួលការព្យាបាលពីគ្រូខ្មែរ ដូច្នេះរដ្ឋាភិបាល និងអង្គការដែលធ្វើការលើផ្នែកពិការសតិបញ្ញា ត្រូវបង្កើតវគ្គបណ្តុះបណ្តាលក្នុងការបង្កើនចំណេះដឹងដល់គ្រូខ្មែរទាំងនោះ ដើម្បីឲ្យពួកគាត់អាចជួយឪពុកម្តាយបានទាំងផ្លូវកាយ ស្មារតី និងផ្លូវចិត្ត។

ការបង្កើតយុទ្ធសាស្ត្រសហប្រតិបត្តិការរួម សម្រាប់បរិស្ថានពិការភាពមេត្រី

អ្នកផ្តល់សេវាគួរធ្វើការឲ្យកាន់តែជិតស្និទ្ធថែមទៀតជាមួយមាតាបិតា មិនត្រឹមតែដោយការបង្កើន និងពង្រឹងការយល់ដឹងរបស់គាត់ពីតម្រូវការឲ្យមានសុខភាព និងអនាម័យល្អប្រសើរជាងមុនប៉ុណ្ណោះទេ គឺថែមទាំងដោយការកំណត់រកឧបសគ្គនានាដែលមាតាបិតាជួបប្រទះក្នុងការរក្សាស្តង់ដារទាំងនេះ និងដោយការសម្រេចចិត្តលើដំណោះស្រាយរួមគ្នាឆ្ពោះទៅរកការសម្រេចគោលដៅទាំងនេះ។ សកម្មភាពស្តារលទ្ធភាពពលកម្មសហគមន៍ជាច្រើនទៀតគួរតែត្រូវបានបង្កើតឡើង ដូច្នេះក្រុមគ្រួសារអាចទទួលបានសេវាសម្រាប់កូនពិការសតិបញ្ញារបស់គាត់។ សកម្មភាពនេះអាចផ្តល់ឱកាសឲ្យឪពុកម្តាយបន្ថែមទៀតក្នុងការរកប្រាក់ចំណូល និងបង្កើនជីវភាពគ្រួសាររបស់គាត់។ មាតាបិតា និងអ្នកថែទាំត្រូវការការប្រឹក្សាយោបល់ជំនាញជាប្រចាំដើម្បីធានានូវសុខមាលភាពកុមារពិការសតិបញ្ញា។ ដូច្នេះមាតាបិតាត្រូវបានលើកទឹកចិត្តឲ្យចូលរួមការពិក្សានានា ដើម្បីចែករំលែកនូវភាពភ័យព្រួយ និងការបារម្ភរបស់ខ្លួនពីអនាគតកូន និងពិចារណានូវដំណោះស្រាយជាក់ស្តែងមួយចំនួនក្នុងចំណោមជម្រើសដែលមានទាំងអស់។ ការបណ្តុះបណ្តាលពីកសិកម្មដល់ក្រុមគ្រួសារ ដូចជាអង្គការមនុស្សលោកថ្មីកំពុងផ្តល់ឲ្យដែលជួយឲ្យមានភាពចម្រុះនៃអាហារប្រចាំថ្ងៃ អាចធ្វើឲ្យស្ថានភាពអាហារូបត្ថម្ភរបស់កុមារប្រសើរឡើង និងផ្តល់អត្ថប្រយោជន៍ដល់សមាជិកគ្រួសារផងដែរ។ ក្នុងករណីខ្លះជនពិការសតិបញ្ញាក៏អាចចូលរួមក្នុងសកម្មភាពកសិកម្មនេះបានដែរ។ ការអប់រំបញ្ចូលគ្នា និងថ្នាក់សមាហរណកម្មគួរតែត្រូវបានអនុវត្ត និងពង្រីកនៅក្នុងសាលារដ្ឋ។ សហប្រតិបត្តិការរួមគ្នារវាងរដ្ឋាភិបាល និងស្ថាប័នក្រៅរដ្ឋាភិបាលគួរតែត្រូវបានគាំទ្រ និងអនុវត្ត។ ដូច្នេះខាងផ្នែករដ្ឋាភិបាលត្រូវអនុម័ត និងអនុវត្តច្បាប់ដែលផ្តល់ប្រយោជន៍ដល់វិស័យនេះ។ ចំណែកឯភ្នាក់ងារអន្តរជាតិ និង អង្គការក្រៅរដ្ឋាភិបាលគួរតែបង្កើតយុទ្ធសាស្ត្រសមស្រប និងបានកែសម្រួលជាមួយគោលនយោបាយរដ្ឋបាលដើម្បីគាំទ្រជនពិការសតិបញ្ញា។

ការនិយាយអំពីពិការភាពត្រូវតែមានលក្ខណៈបញ្ចូលគ្នាបន្ថែមទៀត គឺមិនត្រឹមតែរំលេចអំពីពិការរាងកាយប៉ុណ្ណោះទេ ប៉ុន្តែក៏ត្រូវនិយាយពីពិការសតិបញ្ញាផងដែរ។ កម្មវិធីស្វែងរកមតិគាំទ្រនានា ត្រូវតែបានលើកទឹកចិត្ត និងគាំទ្រ ដើម្បីឲ្យការយល់ដឹងជាសាធារណៈអំពីជនពិការសតិបញ្ញាអាចគ្របដណ្តប់ដល់តំបន់ជនបទនៃប្រទេសកម្ពុជា។ ដូច្នេះការផ្សព្វផ្សាយច្បាប់ស្តីពី

ការការពារ និងលើកកម្ពស់សិទ្ធិជនពិការឆ្នាំ២០០៩ គឺសំខាន់ណាស់ ដែលច្បាប់នេះបានដាក់បញ្ញត្តិថា កុមារពិការសតិបញ្ញានឹងទទួលបានសេវាកាន់តែប្រសើរថែមទៀត ជាពិសេសការប្រឹក្សាយោបល់ពីសុខភាពដោយឥតបង់ថ្លៃ។ ជំហាននានាគួរតែត្រូវបានចាប់ផ្តើម ដើម្បីឲ្យមណ្ឌលសុខភាពនៅជនបទអាចផ្តល់សេវា ឬប្រព័ន្ធបញ្ជូនទៅរកសេវាប្រកបដោយគុណភាព។

បង្កើតស្ថាប័នចំណេះដឹងផ្នែកពិការសតិបញ្ញា

ការស្រាវជ្រាវបន្ថែមទៀតគួរធ្វើការសិក្សាលើផ្នែកខាងក្រោម៖

- ស្ថានភាពកុមារពិការសតិបញ្ញានៅក្នុងសាលា និងវិធីដែលត្រូវបណ្តុះបណ្តាលគ្រូដើម្បីដោះស្រាយនូវស្ថានភាពទាំងនោះ។
- ផលប៉ះពាល់នៃការអប់រំបញ្ចូលគ្នាសម្រាប់សិស្សពិការសតិបញ្ញានៅក្នុងប្រទេសកម្ពុជា។
- ផលប៉ះពាល់នៃបទពិសោធន៍អប់រំផ្សេងៗ ដូចជាថ្នាក់សមាហរណកម្មសម្រាប់កុមារពិការសតិបញ្ញា។
- កម្រិតយល់ដឹង និងបទពិសោធន៍របស់អ្នកផ្តល់សេវាសុខភាព ស្តីពីពិការសតិបញ្ញានៅតាមតំបន់ជនបទ និងទីក្រុង។
- ការយល់ឃើញពីការរើសអើង និងការផាត់ចេញ ដែលទាក់ទងនឹងពិការសតិបញ្ញា។

EXECUTIVE SUMMARY
(English Version)

This report presents the research findings of a project conducted between December 2009 and April 2011 under the support of New Humanity Cambodia, an NGO that serves children with intellectual disabilities and their families. The research was conducted in Boribor district, Kompong Chhnang Province, and used both quantitative and qualitative methodologies, including a survey and in-depth interviews with families of children with intellectual disabilities.

First, the research team conducted a desk review of literature related to the field of disability, and intellectual disability in particular, in Cambodia and neighboring countries. Second, we collected secondary data about prevalence of disability and population demographics from the local authorities and relevant organizations in Boribor District. Third, a survey of 72 families was conducted using questionnaires; 30 of them were receiving NH services while the other 42 were non-NH beneficiaries. Fourth, we conducted individual in-depth interviews with 8 of these families as case studies, 4 of whom were NH beneficiaries. In addition, 13 interviews were conducted with local authorities, 10 interviews with public school teachers and 13 interviews with special needs teachers working with New Humanity. Fifth, we analyzed the quantitative data using SPSS software while for the qualitative data we coded and developed categories to identify themes.

The aim of this research was to conduct a situation analysis of the intellectual disability sector in rural Cambodia by examining the lives of children with intellectual disabilities and their families and by seeking to understand their perceptions and beliefs about disability and intellectual disability in particular. It provides an analysis of the living conditions and challenges faced by families of children with intellectual disabilities as well as the challenges faced by special needs teachers working with children with intellectual disabilities.

The study also sought to learn the attitudes and behavior of families and their extended community (such as siblings, teachers, classmates, and neighbors) towards children with intellectual disabilities, in order to understand how they perceive discrimination. The findings on traditional and contemporary perceptions of disability and causes of disability are included.

Finally, the study sought to identify differences, if any, between the families who are receiving services from New Humanity and the families who do not, in terms of their understanding of the disability, their responses to the disability, and the extent to which the services they receive have had an impact on their daily lives.

FINDINGS ON CULTURAL PERCEPTIONS OF INTELLECTUAL DISABILITY

The Language of Disability

Words to describe a physical disability are preceded by the word "Pikar", whose etymology connotes a "transformation" of condition/status. However, the terms used to describe a person with intellectual disabilities tend to have negative connotations. Although the language used to describe intellectual disability has changed in recent times to less derogatory terms, i.e. ពិការខួរក្បាល [*Pikar Khuo Kbal*], មានបញ្ហាខាងសតិបញ្ញា [*Mien Pañeja Khang Sati Paññaa*], កំសោយបញ្ញា [*Komsaoy Paññaa*] or បញ្ញាអន់ [*Paññaa On*], these changes only occur in educated spheres. The terms for epilepsy are ឆ្កួតជ្រូក [*Chhkuot Chruk*] which literally means “mad pig" and ស្កន្ធម្ដាយដើម [*Skon Mday Deum*] which literally means “evil spirit of one’s previous mother”. This latter term is used also for nerve paralysis, and meningitis.

The spiritual connotation of the terms for epilepsy might indicate why parents believe that epilepsy was associated with evil spirits and that the treatment involved going to the traditional healer.

Religious Beliefs and Perceptions of Disability

Analyzing traditional tales, we found that, in antiquity people with disabilities were recognized but placed in the lowest stratum of the social scale. Paradoxically, in some cases, people with disabilities were also regarded as an important part of the society because they remind us about the fragility of humankind. Other stories confirm this "recognition" of people with disabilities within Cambodian society but the moral at the end of all these stories is the expectation of a complete recovery in order to fulfill the ideal image of a person.

Nowadays perceptions could be divided into two approaches; one that suggests negative responses and another that generates rather positive responses towards intellectual disability.

Traditional folktales and life stories of people with disabilities in antiquity clearly demonstrate the existence of a hierarchical structure in the Cambodian worldview in which existed a scale of values and social acceptance according to the type of disability. In this hierarchy, people with motor impairment (ជនពិការដៃជើង [*Jon Pikar Dai Jeung*]) and deaf people had a higher social status than people with intellectual and mental disabilities (មនុស្សឡប់សតិ [*Monus Lop Sati*]) because they were perceived to have the capacity to “overcome” their disability. On the other hand, individuals with intellectual disabilities were and continue to be denied full acceptance in society and recognized as full citizens because, for example, they are “not even able to get married”, an important indicator of a person's capacity to fulfill their responsibilities within Cambodian society. However, it must be pointed out that, although people with physical disabilities may have more chances for social promotion in contemporary Cambodia, they are still discriminated against and continue to have less access to employment.

FINDINGS ON CHALLENGES FACED BY FAMILIES

Socio-Economic Situation of the Families

The study found that the majority of the families had four or more children, had at least completed primary school and were farmers. They lived in homes made of natural materials (wood, palm leaves or thatch, bamboo) and used bicycles while some had no means of transportation. They did not have steady sources of income, but were dependent on the season for earnings and had difficulty covering daily basic needs.

Although the majority of the families were poor, living on less than 10,000 Riels (approximately 2.50 USD) a day, beneficiaries appeared to have more and steadier sources of income. We may conclude that families receiving services were able to generate more income because they had more work mobility, in that they did not have to provide constant care for their child with disabilities, during which time they were able to work for money.

Families' Access to Antenatal and Postnatal Care

The majority of the families sought antenatal care (ANC). The rest either did not have sufficient funds or did not see the need for ANC. Of those that sought ANC, less than a quarter received an antenatal check-up.

Almost all went to a hospital or clinic for ANC and very few went to a traditional healer or birth attendant. However, although some delivered their baby at a hospital or clinic, the majority delivered their baby at home.

All the mothers sought postnatal care, the majority from traditional healers.

We may conclude that while mothers are more likely to seek postnatal care than ANC, they are also more likely to choose traditional forms of care and healing than modern services in hospitals and clinics, especially during delivery and for postnatal care.

Parents' Perceptions of the Causes of their Child's Intellectual Disability

Parents identified both medically-based and culturally-based causes for their child's intellectual disability.

Parents showed a high level of sophistication in their knowledge of medically-based causes, with most parents identifying maternal or child malnutrition as the cause, and some identifying a high frequency of severe fevers.

Of the second group (culturally-based causes), most parents interpreted their child’s condition in terms of the Buddhist principles of *Karma* and re-incarnation, in which events or acts committed in a previous life determine the outcome and quality of the individual’s current life.

We may conclude that parents attribute intellectual disability to both medical and cultural causes, the latter based on the traditional and Buddhist beliefs of *Karma* and re-incarnation that suggest spiritual or supernatural intervention.

Early Detection

Although all the parents noted the occurrence of specific symptoms, such as frequent high fever or convulsions, the majority did not recognize these symptoms as warning signs of the possibility of developmental disability or intellectual impairment.

All public school teachers and local authorities and many of New Humanity’s preschool staff interviewed also did not connect symptoms as warning signs of intellectual impairment. The special needs teachers at New Humanity’s CBR centers had the most accurate information about prevention, identification and treatment of disability, having received advanced training on these topics.

Most of the parents noticed differences in their child’s development by one year of age. Parents and close relatives were the first to notice these differences in most cases.

Almost 75% sought health from both modern and traditional sources. Of these 85% went to a public hospital or private clinic and 11% went to a traditional healer first.

Over half the parents stated that the professional health providers they sought were unable to recognize their child’s disability. While several received treatment, the treatment the majority (72%) received was prescription pills. Only a few children received or were referred for further treatment or assessment.

Forty-four percent sought treatment a second time; of these, 50% went to a traditional healer.

Parents were more willing to spend money on their child’s treatment if the chances for a cure or better health condition were higher. Parents who attributed the cause of their child’s intellectual impairment to cultural beliefs were more likely to seek help among traditional healers. Although belief in *Karma* generated some level of fatalism, families who were resigned to their situation were more likely to be passive and not seek any services, whereas families who were accepting of their situation were more likely to adapt and look for ways to respond to the needs of their child.

When comparing the two groups, more beneficiaries than non-beneficiaries sought treatment a second time. Besides, more non-beneficiaries than beneficiaries sought treatment among traditional healers in the second round,

We can conclude that the more training stakeholders received, the more likely they were to know about the prevention, identification and treatment of disability. While parents were more likely to seek modern forms of treatment the first time, they became more likely to seek traditional treatment the next time they sought help.

Parents who attributed the cause of their child's intellectual impairment to cultural beliefs were more likely to seek help among traditional healers.

Access to Education

More than half the children had access to educational services, of which almost half went to public schools. Most of these children had mild levels of Down syndrome.

The remaining families did not send their child to school for various reasons, including distance of the school from home, financial constraints, and the belief that the child is unlikely to benefit from an education.

Children with intellectual disabilities, who are perceived to be less likely to benefit from an education, are therefore also less likely to receive an education than children with physical impairments. Additionally, for lack of teaching materials and adaptations, teachers are less likely to accept them in class. Finally, the low status accorded to teachers of children with intellectual disabilities makes it an unattractive job for many, thus reducing the pool of potential teachers.

When comparing the two groups, more NH beneficiaries than non-beneficiaries were satisfied with the quality of the educational services they received. This may be due to the fact that NH provides eight hours of instruction per day, as compared to three hours in public schools, breakfast and lunch, trained teachers with adapted curriculum and materials, individualized educational and rehabilitation plans, transportation by *tuk-tuk* to and from school, individual and group counseling to families as well as agricultural training to diversify the diet and improve the nutritional status of the child. More non-beneficiary families were likely to seek the assistance of friends or neighbors to take their child to school.

Children with intellectual disabilities were less likely than children with physical disabilities to go to school because of the general perception that they would not benefit from an education as well as teachers' lack of specialized training and unwillingness to accept them. Although some children with mild levels of Down syndrome were receiving an education at a public school, parents were more satisfied with the range of services they were receiving from NH. We can conclude that as more teachers receive specialized training and more parents can access auxiliary services in addition to an education, more children with intellectual disabilities will be sent to school.

The Challenges of Raising a Child with Intellectual Disabilities

The most important challenge identified by families surveyed (39%) was the responsibility of having to care for their child with intellectual disabilities at all times.

Another challenge was the need for assistance (specialized or technical help) for their child, especially relating to difficulties with communicating with their child. Other challenges related to money issues, due to health care costs.

About half the parents stated that looking after their child was “just part of their daily life.” This might be explained by pre-determined gender roles whereby mothers are expected to be caregivers, and the Buddhist principle of accepting a given reality.

However, 44% of families stated that the need for constant care and a permanent commitment was tiring and required enormous sacrifices from the family members. Many families showed symptoms of deep physical and psychological exhaustion.

Comparing the two groups, more non-beneficiaries ranked health care costs as a major issue than beneficiaries. This may be because beneficiary children received health care support from NH. On the other hand, more beneficiaries ranked the need for specialized help and difficulties with communication with their child. This suggests that, once families observe the benefits of the services their child receives, they become more aware of the possibilities for development and the need for specialized skills to respond better to the child.

Providing constant care for the child with intellectual disabilities took an enormous toll on families, not only because it precluded the possibility of the parent earning additional income but also because of the physical and psychological impact on family members. Beneficiaries experienced this to a slightly lesser extent than non-beneficiaries as the former had access to educational and health services, which reduced the burden of care and health care costs. However, as beneficiaries began to observe the benefits of these services, they became more specific in their expectations in terms of the need for more specialized skills to respond to their child.

Support Provided to Families

Although beneficiaries constituted almost half the sample, only 37% admitted to receiving some support, perhaps in the hope that they might receive more support or in the fear that the support they currently received might stop.

Most of the families stated that they received support from NGOs, such as NH and Cambodia Trust, while a few received support from public health facilities or neighbors and community.

NGOs are the main source of support for families with children with intellectual disabilities. The limited number of NGO services, especially in rural areas, means that the majority of families will not have access to services for their child.

Parents' Feelings Towards Their Child’s Condition

Parents had positive and negative feelings about their child’s condition. Most of the parents who felt positively towards their child said they felt compassion or pity. Others expressed hope.

Some of the parents who had negative feelings said they felt a sense of hopelessness. Where the disability was severe, parents said they felt despair, which was alleviated by resignation and the belief that this was the child’s *Karma,* which is often interpreted within the western context as a fatalistic approach. However, we found in our study that these parents have two different responses to the disability of their child. One response consisted of adopting an attitude of resignation. This attitude drives the family members to have a passive approach towards the child and does not give a chance to the child to improve their living condition or quality of life. Another response consisted of an attitude of active acceptance that lead the parents to acknowledge the situation as it is (e.g. the disability cannot be cured and will not go away) and then to look forward to what they can do for the well-being of their child.

Comparing the two groups, more beneficiaries expressed pity and hope than non-beneficiaries. Parents who do receive services have a better understanding of their child's condition and have observed the benefits of these services for their child. They begin to feel more optimistic and hopeful about their child's future. In contrast, parents who do not receive services are much more likely to feel hopeless and resigned.

Parents' Experiences with Discrimination

Parents did not perceive their behavior towards their child, which might include pejorative nicknames or keeping the child locked during a visit from professionals, as discriminatory but as indications of affectionate humor and respect for the visitors.

Parents did see the behavior of other community members, such as people not visiting them because they had a child with intellectual disabilities, suggestions to euthanize the child, or not being allowed to bring their child to the pagoda or village festivals, as discriminatory, even as they recognized that their child had less value in society.

NH professionals who had received awareness training about non-discriminatory behavior saw the behavior of both parents and community members as discriminatory and attributed community members' attitudes to the belief that the mother was to blame.

The concept of discrimination depends mostly on how the individual interprets their experience. Community members discriminated against children and families alike by excluding the child from village ceremonies and by blaming the mother for their child's condition.

Parents' Concerns and Expectations for Their Child's Future

A major concern that almost all parents identified was the worry about what would happen if they predeceased their child. Expectations were linked to education, finding a cure, and the hope that the child would become independent in self-care skills.

Asked how they expected to achieve these results, most parents said they placed their faith and trust in NGOs while a few thought that the care the community and family members were providing would be sufficient.

Comparing the two groups, beneficiary families were less worried about their child's future than non-beneficiary families. More beneficiary families saw the need for educational and rehabilitation services to help their child progress than non-beneficiary families.

Parents who were receiving services and support began to see their child improving and growing in skill acquisition. As parents observed their child's progress, they became more hopeful about their child's future. They also became less concerned with finding a cure and were more likely to accept the child's condition and look for ways to respond to their needs.

Challenges for New Humanity CBR Staff

The biggest challenge was teaching hygiene and health care and its importance to the beneficiaries and their parents. Most of the children with intellectual disabilities lived in very unhygienic and unsanitary conditions. All the children lived on the ground and had no access to safe water. Some mothers, who were in charge most of the time, were not strong enough to move their older son or daughter with disabilities to help them use the toilet. The children's health and nutritional status was also a concern for the staff.

Teachers also expressed concern about the widespread practice of self-medicating by parents, sometimes involving wrong or spurious drugs, in their desperate efforts to find partial relief for their child.

The special needs teachers found also the tasks of caring for the children and getting parents to understand the importance of sending their child to school regularly as well as attending the parent training activities very challenging.

All the special needs teachers had completed between grade 9 and 12 of schooling and were more comfortable in learning by imitation ("seeing and doing"), which involves more applied practice, rather than by reading theory or methods through textbooks. However, the limited numbers of trained special needs teachers in Cambodia and the expense of bringing in external or international consultants for training meant that these opportunities for hands-on learning were few and far between, not to mention too short and often lacking in continuity. The teachers were not inclined to supplement their knowledge by reading the extensive material on disability developed by NGOs and other international institutions that was more easily available to them because most of these were in English.

Most of the concerns voiced by the teachers did not match those of the parents'. While parents worried about their child's future, the teachers, recognizing that poor living conditions might preclude the possibility of a future, were worried about the child's present. However, merely giving advice to parents without providing concrete alternatives or suggestions had not had much effect on changing parents' behavior and attitudes towards maintaining hygiene.

RECOMMENDATIONS

We propose a list of recommendations for implementation through mutual collaboration among all the actors involved i.e. people with intellectual disabilities, families, government, and other institutions/organization.

Building Information Systems on Intellectual Disabilities

Family members of the children with intellectual disabilities should have more access to information and, if possible, training on how to care and deal with their children's situation. The more parents are informed and instructed about their child's intellectual disability, the more parents feel involved and are eager to do something to help their child. Possible topics of training might be:

- What is disability (intellectual disability) and its health and social implications.
- Kinds of intellectual disabilities, especially those common in the Cambodian context, and its particularities.
- Early prevention and detection as well as treatments possible, so parents can also be involved in physiotherapy and other specific therapies according to the disability.
- Basics of sanitation, safe water, and personal hygiene.
- Adverse effects of self-prescription.
- Educational options available and later possibilities for employment, as appropriate
- Legislative and policy mandates that relate to individual and parental rights and service provision.

Dissemination and training about these topics should target all stakeholders, including parents, teachers and doctors, towards the successful inclusion of children with disabilities, as mandated in the *2009 Law on the Protection and the Promotion of the Rights of Persons with Disabilities.*

A culturally-responsive approach should be considered in the dissemination and training. Changes in the language of disability might be the first step to transform negative perceptions of people with intellectual disabilities. Therefore, terms to refer people with intellectual disabilities with less or no negative connotations should be taught and disseminated.

Service providers should not try to change the people's traditional beliefs about causes of intellectual disabilities, but instead show an attitude of respect accompanied by more effective campaigns of information.

Building Skills to Work Effectively with People with Intellectual Disabilities

More programs and trainings should be developed and provided to school teachers by introducing them to special curriculum and techniques on how to teach children with intellectual disabilities. The more teachers who receive specialized training, the more parents can access educational and auxiliary services, and the more children with intellectual disabilities will go to school.

More health care providers need to receive specialized training on maternity care as well as on intellectual disability. Parents' use of public facilities should be encouraged by building a common strategy between parents and health care providers.

Each child with intellectual disabilities should be treated as unique. Parents, family, and special caregivers must be encouraged to improve the quality of life of children with intellectual disabilities.

Service providers, parents, relatives and community in general must learn to recognize and advocate against acts of discrimination inside and outside their communities.

Since many parents of children with intellectual disabilities continue to seek health care among traditional healers, government and NGOs working within the sector of intellectual disabilities must develop trainings to upgrade the knowledge of these traditional healers, so they can help parents with physical, mental and emotional states.

Building Common Strategies of Cooperation for a Disability-Friendly Environment

Service providers should work more closely with parents not only by increasing and strengthening their awareness of the need for better health and hygiene at home, but also by identifying the barriers parents experience in maintaining these standards and mutually deciding on practical solutions towards achieving these goals.

More CBR programs and activities should be established, so more families can receive services for their children with intellectual disabilities. This would give parents more opportunities to generate income and eventually improve their family's livelihood.

Parents and caregivers need professional and regular counseling to ensure the well-being of children with intellectual disabilities. Thus parents should be encouraged to engage in discussions to share their fears and concerns for their child's future and consider some practical solutions among the options that may be available

Agricultural training to families, such as NH is providing, which helps to diversify the diet can improve the nutritional status of the child and benefit all family members as well. In some cases, people with intellectual disabilities can be also involved in these agricultural activities.

Inclusive education and integrated class should be implemented and expanded within the public schools.

Mutual cooperation between government and non-government institutions should be supported and reinforced. Thus government, on one hand, must enact and enforce laws that benefit the sector. On the other hand, international agencies and NGOs should develop appropriate and adapted strategies in line with the administration’s policies in favor of people with intellectual disabilities.

The discourse on disability has to be more inclusive, highlighting not only issues relating to children with physical disabilities but also children with intellectual disabilities.

Advocacy programs must be encouraged and supported, so public awareness of people with intellectual disabilities can be spread out throughout rural Cambodia. Thus dissemination of the 2009 *Law on the Protection and Promotion of the Rights of People with Disabilities*, which mandates that children with intellectual disabilities will have greater access to services, and in particular free consultation for health care, is crucial. Steps to enable rural health care facilities to access a qualified service or a system of referral should be taken.

Building a Body of Knowledge on Intellectual Disabilities

Further research should be done in the following issues:

- Situation of children with intellectual disabilities in the schools and how teachers are trained to deal with these particular situations.
- Impact of inclusive education for students with intellectual disabilities in Cambodia.
- Impact of other educational experiences like integrated classes for children with intellectual disabilities.
- Current level of knowledge and experience on intellectual disabilities of health providers in rural and urban areas.
- Perceptions of discrimination and exclusion relating to intellectual disabilities.

INTRODUCTION

Due to the country's turbulent history of war and violence during the Khmer Rouge regime there is a high rate of physical disability in Cambodia, especially caused by landmines. Government and international intervention has yielded good results over the years. For instance, the number of casualties from landmine accidents has gone down from more than 2,000 annually in the early 1990s to less than 500 in 2006. However, physical disability is just a part of this sector. The lack of data, quantitative or qualitative, about people with intellectual disabilities is a major concern.

There is some controversy relating to quantitative data on people with disabilities: According to the 2004 Cambodia Socio-Economic Survey (CSES), the estimated population with some kind of disability was 4.7 percent of the total population, while the 2008 National Census determined that only 1.4 percent of the country's population was disabled[1]. The situation becomes even more complicated when we consider intellectual disability. For example, CSES (2004) does not use the term "intellectual disabilities" but provides data on several categories that could include intellectual disabilities; for instance, mental (8.7%), learning difficulties (1.2%), and seizures/epilepsy (1.4%). Therefore, it is not easy to provide clear statistics of people with intellectual disabilities. According to the 2008 Census, the population of people with "mental disability" is currently about 12.6 percent of the total population of people with disabilities, but there is no information on how this category is defined and on what basis people were identified.

Table 1: Figures on Disability by Source

Source	Number/percentage of disabled people
According to ADB report in 1997 *Identifying Disability Issues Related to Poverty Reduction: Cambodia Country Study*	9.8% of the population were living with disability
According to UNDP report in 1999	15%
According to NIS in 2004, *Socio-Economic Survey*	4.7%
According to Cambodian Demographic Survey Report in 2005	2.2%
According to General Population Census of Cambodia 2008.	1.44%

According to World Health Organization[2] which represents the predominant western science, the causes of intellectual disability can be regrouped in categories related to time regarding the birth of the child. Thus, the causes might arise before birth (prenatal), around the time of birth (perinatal), and after birth (postnatal).

According to the information handbook of the Disability Action Council[3] (DAC: 2001), prenatal causes are linked with chromosomal disorders (i.e. Down Syndrome) and single gene disorder (i.e. brain malformations like microcephaly). During this period other

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[1] According to Census 2008, the figure of disability in Cambodia is 1.44% of the population or 192,538 people. However, according to Handicap International, even though the CSES 2004 has some inaccuracy, it is most reliable among all the statistics.

[2] http://www.searo.who.int/en/Section1174/Section1199/Section1567/Section1825_8090.htm

[3] Children with Special Needs in the Classroom, Information Handbook. DAC, Cambodia, 2001.

environmental influences could affect the new born i.e. iodine deficiency, severe malnutrition in pregnancy, abuse or exposure of harmful substances (drugs, alcohol, chemicals), and maternal infections like rubella or syphilis. Most of the causes noted above are preventable, especially those related to environmental influences and harmful substances. However, these causes are still very common in developing countries, like Cambodia, where the poor living conditions of most people make them highly vulnerable.

Perinatal causes are associated with complications of pregnancy, maternal diseases (i.e. heart, kidney, and diabetes), placental dysfunction, severe prematurity, difficult delivery, birth trauma, severe jaundice, and hypoglycemia.

Postnatal causes are connected to brain infections, i.e. tuberculosis, encephalitis, bacterial meningitis. These causes are also linked with head injuries, severe and prolonged malnutrition of the child and finally gross under-stimulation. Therefore, we could state that causes of intellectual disability are the combination of biological and socio-psychological factors.

While Carter (2009) stated that high fever and congenital factors were the main causes of intellectual disabilities in Cambodia, VanLeit, Prum and Samol (2007) found that the majority of parents (62%) attributed causes to high fever and convulsions.

Just as it is important to know the causes of disability, a study to understand the attitudes and behavior toward children with intellectual disabilities is equally important. The diagnostic of the disability is just the first step, perhaps just the beginning of a long way to go. How family and community perceive a child with intellectual disabilities is a crucial step to cross the threshold between discrimination and acceptance. "The initial response of parents and the broader community to a child with birth defects is guilt and embarrassment"[4].

In this study we attempt to explore and understand the attitudes and behaviors that families and community have towards these children, and how NGOs can help in this process of adjustment and change perception. Moreover, it was important to identify how factors such as education, income, and especially cultural beliefs play a decisive role in terms of perception and behavior towards children with intellectual disabilities.

Currently, there are just a handful of organizations working with children with intellectual disabilities in Cambodia. Further, most of them are located in urban areas, although 80.6% of Cambodia's population live in rural areas (National Institute of Statistics, 2008) and experience challenges quite different from those in urban areas. For instance, because of extremely limited road connectivity in rural areas and isolation of villages in remote areas, issues of access to health and educational services and information are more acute than in the national and provincial capitals.

We believe that with more and accurate information about the lives of children with intellectual disabilities and their families, we can respond better to their needs. The data on disability are insufficient at national level and not completely updated. The information on the situation in rural areas is even more limited. Quantitative data are needed, for

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[4] Ravindranadan, V. & Raju, S. "Adjustment and attitude of parents of children with mental retardation" Journal of the Indian Academy of Applied Psychology, 2007, Vol. 33, No. 1, p. 137-141. Retrieved from http://medind.nic.in/jak/t07/i1/jakt07i1p137.pdf.

example prevalence and incidence rates, to clarify the magnitude of the problem and for planning purposes towards developing services. But, more significantly, there is an acute need to explore and understand more about intellectual disabilities from the perspectives of those who live with it on a daily basis. This study will provide qualitative perspective with insights that have not yet been investigated within the rural context in Cambodia regarding intellectual disabilities.

CHAPTER 1
Research Design and Methodology

1.1 Rationale of the Study

Public and non-governmental services for people with disabilities already exist in Cambodia, especially in urban areas. However, it is not known to what extent cultural attitudes and beliefs may affect utilization of these services by rural populations, or how the absence of these services might present challenges and affect the living conditions of families with children with disabilities. It is also crucial to understand the situation of families in terms of economic status, health condition, access to education, and the discrimination they experience. Parents or relatives may consider it a burden to spend time caring for their child with disabilities instead of developing other activities to generate income. Parents may ignore the situation of their children with disabilities in order to avoid social discrimination within the community. By arriving at a better understanding of what intellectual disability means to families and the challenges such condition presents to them, professionals can begin to (a) develop services that are more closely attuned and responsive to families' needs and (b) advocate on their behalf for improved health care and assistance, such as early detection and prevention, and increased social inclusion and legal rights.

This study aims to contribute to the body of knowledge on intellectual disability in Cambodia by providing a qualitative analysis of the current situation in Boribor district. Although the sample size is limited, the findings can be generalized across other rural locations in Cambodia, especially in the low lands where population socio-cultural characteristics are similar.

In this research there were two groups of informants, one called "beneficiaries" and formed by families receiving services from CBR centers supported by New Humanity, and the other one called "non-beneficiaries" and including families who do not receive these services. The reason for choosing these two groups was to identify to what extent the work of the CBR centers support the families to respond to the challenges of caring for a child with intellectual disabilities.

Since the focus of the study was to understand the perceptions of families of children with intellectual disabilities and the ways they cope with disability on an everyday basis, a qualitative approach was particularly appropriate; however, quantitative data was also collected to find out the parents' daily challenges.

Finally, we believe that this study may become a resource and tool for further studies on other aspects like access to education, staff training on intellectual disabilities, importance and role of family members for the improvement of children with disabilities through the acceptance of their child's impairment.

1.2 Objectives of the Study

The main aim of this research was to understand the situation of intellectual disability in rural Cambodia by documenting detailed accounts of the lives of children with disabilities and their families. In collaboration with the Ministry of Social Affairs, Veterans and Youth Rehabilitation and other NGOs concerned, New Humanity Cambodia attempted to achieve the following objectives:

- Identify and analyze the traditional and contemporary perceptions of Cambodian families on disability and its causes, with an emphasis on intellectual disability.
- Develop an understanding on the living condition and challenges of children with intellectual disabilities and their families. As we learn about daily life of these families, we gain a better understanding about the challenges they face.
- Understand the feelings, attitude and behavior of families and their extended community (siblings, teachers, classmates, and neighbors) towards people with intellectual disabilities.
- Identify differences, if any, in the challenges and impact of the disability between families who receive services from New Humanity and those who are not receiving services from NH's CBR centers.
- Identify the challenges that teachers from public school as well as from CBR centers face regarding their work with children with intellectual disabilities.

1.3 Research Setting

The province of Kompong Chhnang is situated in central Cambodia, 200 km to the south of Battambang city and about 95 km to the north of the capital city Phnom Penh. Crossed by the Tonle Sap River, the province covers an area of 5,521 km^2, i.e. 3.1% of the Cambodian land area.

Table 2: Kompong Chhnang Population by Age Group

Age Group	%
Under 5 (0-4)	**12.1**
Children (0-14)	**35.8**
Economically productive age group (15-64)	**59.6**
The elderly population (65+)	**4.5**
The voting age group (18+)	**52.3**

Source: General Population Census of Cambodia 2008

The total estimated population, according to the last Census 2008, is 472,341 people or 4.1% of the total population in Cambodia, with around 48.1% male and 51.9% female. More than 85% are farmers, and because of its closeness to the biosphere of Tonle Sap Lake, the rest of the people (mostly Vietnamese communities) are fisherman. The average household size is 4.6 people and the average density is 99 people per km^2. This province has a poverty rate of 42.7% within the Tonle Sap Zone, as compared to the coastal zone which has a poverty rate of only 28.8% percent and the Phnom Penh zone of only 4.6% (the mountain zone is the poorest among all)[5]. More than one third of the population in Kompong Chhnang is composed of children under the age of 14 years, as shown in Table 2.

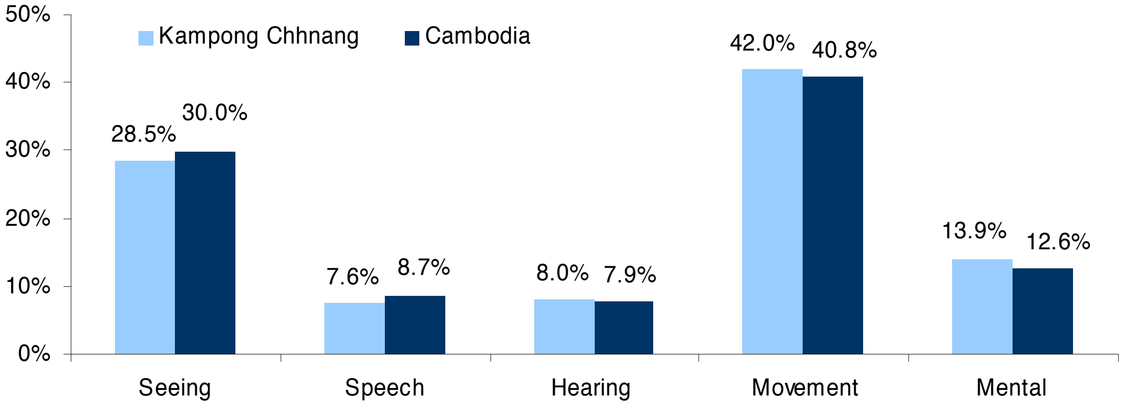
Table 3: Demographic Data of Kompong Chhnang by District

No	Districts of Kompong Chhnang	Population			Families	
		Total	M	F	Number	%
1	**Boribor**	**56,406**	**26,632**	**29,774**	**12,622**	**12.5**
2	Cholkiri	32,048	15,920	16,128	6,058	6.0
3	Kompong Chhnang	43,130	20,788	22,342	8,411	8.3
4	Kompong Leang	44,520	21,841	22,679	8,947	8.8
5	Kompong Tralach	80,835	39,042	41,793	17,254	17.0
6	Rolea Bier	92,715	43,266	49,449	20,983	20.7
7	Samaki Meanchey	65,754	32,124	33,630	14,419	14.2
8	Tuek Phos	56,933	27,394	29,539	12,566	12.4
TOTAL		**472,341**	**227,007**	**245,334**	**101,260**	**100%**

Source: General Population Census of Cambodia 2008

Our targeted area in Kompong Chhnang was Boribor district, composed of 11 communes (Anhchanh Rung, Pech Changvar, Popel, Chak, Trapeang Chan, Ponley, Chhnok Tru, Kon Rang, Phsar, Melum, Kampong Preah Kokor).

Figure 1: Prevalence of People with Disabilities by Type of Disability in Cambodia & Kompong Chhnang



Source: General Population Census of Cambodia 2008

The research location can be justified by two main reasons. First, New Humanity has been working in this geographic area since 2003 and started a program for children with

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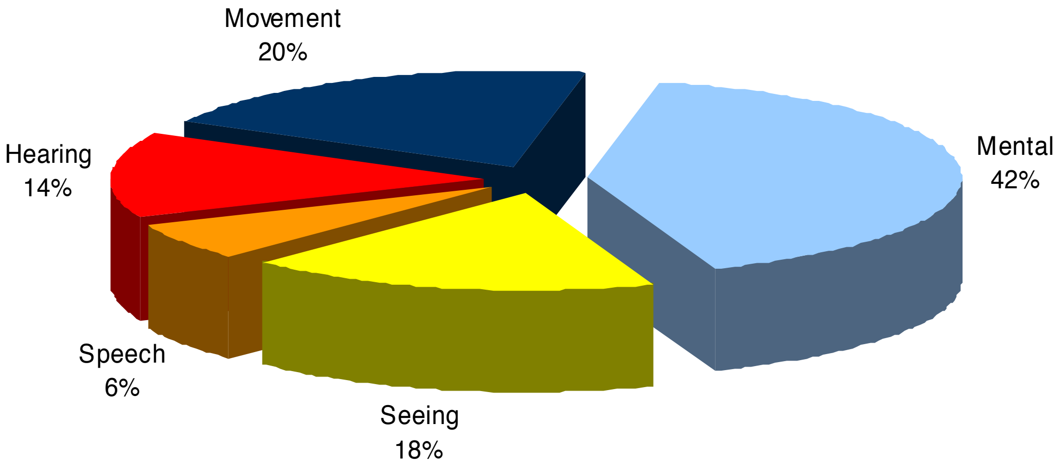
[5] Poverty Profile of Cambodia. Royal Government of Cambodia, Ministry of Planning, 2006.

disabilities in 2006, which provided us easier access to families for data collection. Second, according to the General Population Census of Cambodia (2008), prevalence rate of disability is much higher in Kompong Chhnang province (4.2%) than at the national level (1.4%). Thus, according to this Census, among a total population of 8,024 people with disabilities, the distribution by type of disability in Cambodia is 42.0% for motor impairments, 28.5% for seeing impairments, 13.9% for mental impairments, 8.0% for hearing impairments and 7.6% for speech impairments. These figures are slightly different in the case of Kompong Chhnang province, as displayed in Figure 1.

In order to have more accurate data about our targeted area, Boribor District, we collected data directly from the Provincial Office of Social Affairs, Veterans and Youth Rehabilitation (PoSVY). PoSVY provided us with updated data about the prevalence of people with disabilities following the same categories used by the 2008 Census. Figure 2 below shows us clearly the differences between the data at district and national levels. The PoSVY could not give any explanation about these differences on figures, nor could we find any apparent causes. We might speculate that data collectors at the district level focused on the CBR centers of NH to gather information about the location of people with disabilities. Therefore, since NH focuses on intellectual disabilities, the information collected may be biased in favor of this kind of disability.

In any case, so far there are no reliable statistics of disability prevalence at any level. This statement is supported by the assumption shared among agencies working in disability sector that the 2008 General Census gives us an inaccurate low prevalence rate of disability in Cambodia.

Figure 2: Prevalence of People with Disabilities by Type of Disability in Boribor district



Source: Provincial Department of Ministry of Social Affairs, Veterans and Youth Rehabilitation: June 2008

This inaccuracy of figures might be related with factors such as geographic location, since households are scattered all over the province which creates an obstacle of access. Another reason lies in the lack of adapted formal assessment tools for identifying children with intellectual disabilities, especially in cases where the condition is less visible. Finally, because of social stigma, individuals are sometimes hidden by their own families.

1.4 Scope and Methodology

The research was conducted in five stages.

- In the first stage, we conducted a desk review of literature related to the field of disability, and intellectual disability in particular, in Cambodia and neighboring countries.
- For the second stage, the research team collected secondary data about prevalence of disability and population demographics from the local authorities and relevant organizations in Boribor District. Moreover, this stage provided us a bird's eye view of the locations with a major prevalence of disability.
- Once we obtained this information we moved into the third stage, in which a sample of 72 families were surveyed in Boribor district; 30 out of 72 received services from NH's community-based rehabilitation (CBR) centers and activities while the other 42 did not receive NH services. This information included the living conditions, number of people with intellectual disabilities, access to services such as health care and education, and the challenges experienced by families with children with intellectual disabilities, and finally the general perceptions towards children with intellectual disabilities. In order to triangulate the data, we also conducted interviews with other key informants, including: (a) 13 neighbors and local authorities composed of commune leaders, commune council members, and village leaders; (b) ten public school teachers, who have some students with learning difficulties within the district of Boribor; and (c) 13 special needs teachers of New Humanity CBR centers.

Data collection among non-beneficiaries

Our purpose in including families who were not receiving services from NH in the sample was to enable us to make comparisons between the two groups and ascertain if there were any differences in their capacity to support their child, particularly in terms of their help-seeking behavior, and their perceptions of disability.

The data collection among the non-beneficiaries was done in 4 steps.

First, we contacted the commune chief to ask about the prevalence of people with intellectual disabilities in their community.

Second, we visited 16 villages within 5 communes and established contact with 42 families to locate them, verify that they have a child with intellectual disabilities and confirm their willingness to participate in the survey.

Third, we asked the commune leader to set up a timetable for our interviews, so the families would not be bothered by our unexpected presence.

Fourth, we proceeded to conduct the survey, using questionnaires, followed by the in-depth interviews with the families. Most interviews were conducted in the families' own houses. In some cases, because of the difficulty of transportation, especially in Chhnok Tru (floating village on the Tonle Sap Lake) the interviews were conducted in the commune hall.

- Then in the fourth stage we conducted in-depth qualitative interviews with eight families, selecting four from each group (NH beneficiaries and non-NH beneficiaries), towards developing case studies (see Table 4). Several interviews were conducted with each family in the family's home environment and included participant observations to develop an understanding of their daily lives and the challenges they faced.

Table 4: List of Case Studies

N.	Name	Status	Age	# of Siblings	Impairment	Parents' Occupation
1	Soy Chiva (passed away)	Beneficiary	7	2	Microcephaly	Farmer
2	Chhin Huort	Beneficiary	15	7	Cerebral Palsy	Farmer
3	Kao Pisey	Beneficiary	3	5	Mental retardation	Street Vendor
4	Rin Suvanna	Non-beneficiary	6	4	Hydrocephaly	Farmer
5	Ros SokChea	Non-beneficiary	10	4	Bacterial Meningitis	Farmer
6	Pech Sobol	Non-beneficiary	5	3	Down syndrome	Farmer
7	Thit Chan Vinh	Non-beneficiary	9	4	Down syndrome	Farmer
8	Seoun Kunthy	Beneficiary	7	5	Down syndrome	Farmer

- In the fifth stage, we analyzed the quantitative data using SPSS software while for the qualitative data we coded and developed categories to identify themes.

CHAPTER 2
Disability in the Cambodian Context

2.1 Defining Disability in Cambodia

In Cambodia, there is not yet a uniform definition of disability. The lack of an accorded definition of disability has pushed researchers to use imported definitions according to different socio-cultural contexts rather than a definition based on Cambodia's reality. An example of this is the study on "Toward a cooperative approach: A study on the situation of children with intellectual disabilities in Cambodia", conducted by J. Carter (2009), which uses the definition[6] of the American Association of Intellectual and Development Disability. However, these discrepancies are not exclusive to Cambodia. In other countries, too, the definition of disability is being debated, depending on the approach taken by the people working on this issue.

A report by CCC (2006) on "The Challenge of Living with Disability in Rural Cambodia" does provide an interesting definition of disability and the difference between disability and impairment. According to the authors, "impairment" is referred to "the personal condition in which the person is limited in his or her personal or social ability to function." People with impairment may be affected by the limitations of their biological dysfunction. However, "disability" is referred to the result of the interaction of the individual with the "social and physical environment" in which he or she can face social discrimination from their family member or people in the society because of their impairment, which increases the effect of the impairment and results in their becoming disabled. This bio-psychosocial definition of disability emphasizes the rights-based approach, in that it places the responsibility on society to adapt, without negating the impact of a biological loss of function in the individual with the impairment. Through the 2007 UN Convention on the Rights of Persons with Disabilities, this has now become the universally recognized definition.

In contrast, government ministries in charge of drafting Cambodian disability law have created a common definition that focuses mostly on the medical approach, which tends to place the responsibility on the individual with the impairment to adapt to the norm. Thus, they define people with disabilities as "any citizen who lacks any physical organ or capacity or suffers any mental disability, that causes restriction to his or her daily life or social activities and which significantly causes differences from non-disabled people, and who has a disability certification from the Ministry of Health".

This official classification may be helpful for teachers, in order for them to have an idea about the main categories, its definitions and description of disabilities. Nevertheless, there is still a lot of work to be done in terms of accurate assessment. The official classification of disability developed by the Ministries of Health and Social Affairs with technical assistance from UNICEF also has some shortcomings (Kalyanpur, 2010). One, there is lack of clarity on the meaning of each category, indicated by the comparatively

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[6] Intellectual disability is defined as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills, originating before the age of 18."

high number of cases included under the category of “other” in EMIS. Two, while seemingly dissimilar conditions, like cerebral palsy and children with “timid behavior” are clubbed together within the same category of “learning difficulties”, conditions like hypo/hyper-glycemia, fits/convulsions, and leprosy that could be placed under an umbrella category of “health impairments”, are separately classified under “fits/convulsions” and “sensory difficulties”.

This study found that, despite the existence of this classification system, care givers in rural areas or CBR centers, do not really grasp the meaning of some categories, for example “strange behavior” and “learning difficulties”. This lack of understanding makes the process of assessment difficult, and children may be placed under a category that does not reflect their condition accurately. The work becomes even harder when the staff have to deal with children with multiple disabilities, as most professionals do not have enough experience and knowledge to distinguish between the primary and secondary disability.

So far policies are strongly focused on people with disabilities, which represent an important step forward. However, the success of the *Law for Protection and Promotion of the Rights of Persons with Disabilities* is contingent on its effective implementation and enforcement. Programs for parents, caregivers and teachers need to be promoted and implemented to transmit knowledge about intellectual disability.

2.2 Cambodian Statistics on Disability

Therefore, without a clear workable definition accordingly to Cambodian context, there is always the risk that some disabilities might be misidentified or overlooked. This is even more so for a category like intellectual disabilities, where conditions are so varied and encompass a broad spectrum of behaviors. A good example of such discrepancy is illustrated in Table 1 which shows different figures for the prevalence of disability in Cambodia depending upon the source. Such a lack of accurate figures raises the concern that the sector might continue to remain vulnerable to being excluded from national policies.

Handicap International (2009), in its briefing paper, found some weak points in the statistics from the 2004 CSES, such as the fact that this survey did not cover the whole country and excludes people living in institutions. In spite of such inaccuracies, this source was considered by NGOs as the most reliable data among all statistics in Cambodia at that time. The 2008 Population Census provides us with new and updated information about the sector, but again, discrepancies in identification criteria affects the accuracy of these figures.

Besides the issues of statistics, when speaking about disability, there is a tendency to focus primarily on physical impairments. For instance, in its 2008 annual report, Cambodian Disabled People’s Organization (CDPO), by mistake, refers the 658,000 people with disabilities (or 4.7 % of the total population) as "physically disabled people”.

Overall, inaccuracies result from the lack of human resources specialized in this field. There are only a few people who have some skill to understand the variety and implications of disability. Carter's study (2009) found that some NGO staff working in the disability sector did not have an understanding of the basic characteristics of intellectual disability. This indicates an acute need for trained data collectors who are able to identify and classify people with disabilities systematically.

Taking into account the reality of the lives of people with intellectual disabilities, this research study sought to develop a definition on the premise that intellectual disability is a concept with multi-faceted meanings that are based on the understanding of people interviewed. In this context, we found that the definition is somehow constructed between conventional understandings, cultural beliefs, and the physical situation of the persons with disabilities themselves. These three factors influence directly the help-seeking behavior of parents for their children with intellectual disabilities.

2.3 Discrimination Against People with Disabilities

Discrimination can originate from many different sources, including health, cultural, and social factors. For the medical model, which predominated in many western countries, intellectual disability is considered a disorder that impairs a correct cognitive functioning and then involves adequate treatment and assessment. Such definition sees the person as the problem and overlooks the role that society plays in this discrimination. This model has since been discredited.

Since children with intellectual disabilities require adapted education and rehabilitation services for improvement, the follow-up is a life-long process. However, Cambodia still lacks developed health care and education systems for such children. Therefore, most of the time, families have to carry all the responsibility of caring for the child with intellectual disabilities. As a result, many families look for assistance from an organization or institution where some kind of specialized service is offered. However, in Cambodia, these institutions are very few, and most of them are located in the capital city or in provincial urban areas.

According to the Asian Development Bank [ADB] (cited in CCC, 2006), the presence of one member with disabilities in the family can lead to higher expenditures which may push the family into debt or force them to sell their assets to pay for treatment. Besides, one of the parents cannot help to generate income for the family due to the time dedicated for providing care (Carter, 2009). Consequently, health care and attention provided to people with disabilities becomes a long-life burden, especially when families realize that their child cannot be treated adequately due to the lack of human resources specialized in this sector.

Social discrimination may lead the family and community to some actions that affect the rights and the livelihood of children with disabilities. ADB (cited in CCC, 2006) reports that the social status of persons with disabilities in Cambodia is so low as to be practically non-existent in some cases. According to the report people with disabilities represent the poorest group in Cambodia, completely dependent on the charity and compassion of others, including family. Such dependence reflects that they do not have the option to choose what they want but must rely entirely on their caregiver's will. As a result, according to CDPO's annual report (2008), people with disabilities are still excluded from community development projects. This translates into exclusion from other basic human rights, such as access to basic education and vocational training, employment, and electoral franchise. According to the CCC report (2006), children with disabilities are not sent by their parents to school because they feel embarrassed and uncomfortable when others stare. In some cases some children with disabilities do not wish to go to the school because of a fear of being teased by other children, classmates or neighbors.

A report by Kalyanpur et al. (2007) describes the experience of a 16 year old girl whose neighbor told her that she did not need to study because she was blind. In some cases, a number of school teachers advised parents of children with disabilities not to bring their child with disabilities to study, because they believed that the children would require more special care and attention, and become an additional burden for the teachers. This opinion is widespread among teachers who are not informed about the rights of children with intellectual disabilities. Children who cannot access a basic education have fewer chances to find simple jobs that would give them a level of independence. Thus, some people with disabilities in urban areas have no choice or are forced by their relatives to beg in the streets, since this can earn them an average of 1 to 2 dollars per day[7]. This activity, considered negative, is the least desired occupation in Cambodian society and is also an unsteady source of income[8].

Our study found that family members and neighbors used different names to call to people with disabilities instead of using their first name. Some of these nicknames are "stupid" (អាល្ងង់ [*A Laa Ngung*]), "cripple" (អាខ្វិន [*A Kvin*]), "blind" (អាខ្វាក់ [*A Kvak*]). Cognizant of the derogatory connotations of these names, people with disabilities believed that they were being made fun of and felt ashamed and sad. For some children, their defense mechanism was to drop out of the school and avoid social interaction with other people. In some extreme cases, children with intellectual disabilities were restricted to their homes, and locked up or tied with ropes by their parents or relatives to avoid insults or causing shame to the family. Actions like these only served to further the stereotype that people with disabilities were akin to animals or a source of danger to others. Besides, while people with physical impairments, like amputees and blind, are, relatively speaking, more likely to be re-integrated or rehabilitated into society with some vocational skills, people with intellectual disabilities and mental illness are considered difficult cases to care for and educate because “they require too much time”.

It must be noted that the study by Carter (2009) found contradictory data. According to this report, parents claimed that most neighbors felt only pity (អាណិត [*Annit*]) for their children even though the NGOs and service providers insisted that the children did experience very strong discrimination.

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[7] It should be noticed here that even some kinds of people with disabilities especially the amputees (which have better status than people with intellectual disabilities) received some vocational training, they could not survive with those skills since they could not earn much from those low income jobs. This is proved by the report released recently by Handicap International titled "Voices from the Ground: Landmine and Explosive Remnants of War Survivors Speak Out on Victim Assistance", according to which 2/3 of the 78 respondents reported that economic reintegration opportunities had not improved since 2005.

[8] For more information on the lives of street beggars, please read: Chrann Chamroeun and Robbie Corey-Boulet, Friday 04, 2009. Land Mine Victims Face Bleak Prospects: A Survey. Phnom Penh Post.

2.4 Identified Causes of Disability

Research indicates that poverty is both a cause and consequence of disability (World Bank, 2005). For instance, as a result of poverty, pregnant women may become malnourished and are more likely to have malnourished children, putting them at risk of developing intellectual disabilities. Given that the study conducted by VanLeit et al. (2008) reports that nearly 50% of the households interviewed earned less than 1 USD per day, the issue of poverty is a matter of real concern. In addition, poor families will have limited access to health services, because they cannot afford doctor's fees or to forgo the income lost in going to see a doctor. As a result, conditions which are preventable or easily treated become lifelong disabling conditions.

Despite research indicating that conflict and war in Cambodia have resulted in high incidence of disabilities (Powell, 2003), according to VanLeit, 40% of the 500 household surveyed, reported that *"their child had something wrong at birth (congenital condition)"* and 46% reported sickness as the main cause.

Most of the parents do not have basic education on health care so they do not know how to prevent their children from being seriously sick and eventually becoming disabled. Some parents do not even know that there are some services available that can help treating their children at the first stage, and sometimes the cost of that service is the barrier for them to bring their children to receive basic service.

While poverty is seen as the general cause of disability, the evidence also supports that in some cases, poverty is the consequence of disability due to the amount of expenditure assigned to special care and medical treatment for children and people with disabilities. Besides, one member of the household, in most of the cases, has to remain permanently at home, especially mothers, who are expected to take care of their children and the child with disabilities. This role limits the mobility and accessibility of women to attend trainings on life-skills in order to improve their chances to generate some income for the family.

2.5 Existing Legal Tools and Advocacy for People with Disabilities and Their Families

In Cambodian legislation, specific articles mandate support for the rights of people with disabilities. For example, article 31 of the Cambodian Constitution states that "every Cambodian citizen shall be equal before the law, enjoying the same rights, freedom and fulfill the same obligations regardless of race, color, sex..." Article 74 added, "The state shall assist the disabled and the families of combatants who sacrificed their lives for the nation". However, the aforementioned article does not specify the kind of assistance or the provisions in which the government could be involved or other agencies in order to create programs to support this sector.

On becoming a signatory to UNESCAP's Proclamation on Full and Equal Participation of the Decade (1993-2002) for Disabled Person in Asia and Pacific in September 2001, and the 2007 UN Convention on Rights of Persons with Disabilities, the government has shown interest in passing a specific law on the rights of persons with disabilities. The Law was first drafted in 1996. In February 2000, a Legislation Working Group comprised by the

Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY), Ministry of Justice (MOJ), Ministry of Education, Youth, and Sport (MoEYS), Ministry of Women's Affairs (MoWA), Disability Action Council (DAC), and Cambodian Disabled People's Organization (CDPO), with Japanese advisors, was set up to review the draft legislation. In 2005, the draft was finalized and, in early 2009, approved by the Council of Ministers. Finally, in May 2009, the Royal Government of Cambodia (RGC) adopted the *Law on The Protection and Promotion of the Rights of People with Disabilities* and the law was declared by Royal Decree on 3rd July 2009.

Even though it has been a time-consuming process, the new legislation is very substantive since it comprises many provisions that people with disabilities can benefit from. For instance, people with disabilities are protected by the law from being abandoned, neglected, or discriminated. Both nodal ministry (i.e. Ministry of Social Affairs) and line ministries (e.g. Ministries of Health and Education) are mandated to set up supported programs such as providing health care, education, rehabilitation centers and vocational skill, and fund or economic incentives (tax-reduction) for people with disabilities or their family. Most significantly, this is the only explicit legal tool that also includes people with intellectual disabilities.

However, despite the 2009 Law, it should be also noted that there are some challenges regarding these legal issues. For instance, there continues to be a lack of understanding about disability and limited efforts to mainstream disability within the national development plan or to include people with disabilities as either participants or beneficiaries (Vinal, 2009). Another challenge is the poor organization of people with disabilities who have limited capacity to structure their own advocacy activities towards claiming their own rights to job opportunities. As most of the services for people with disabilities are provided by NGOs and other organizations funded by foreign donors, there is a risk in terms of sustainability for this sector. As long as public programs are not yet developed, support and equal rights for this sector remains uncertain.

An equally significant challenge is the need for the government and organizations working in the sector to consider and respond to the needs of parents, siblings and the community in general. In the law there are only two articles referring to parents or family members. Article 13 defines the obligations of parents and guardians while Article 16 states that:

> *Ministry in charge of Social Affairs in collaboration with the ministry in charge of Health shall provide training to families whose members are disabled, persons with disabilities and volunteers on methodologies of care-taking and rehabilitation for specific types of disabilities to enable persons with disabilities and their families in the rehabilitation of persons with physical and mental disabilities*[9].

It is clear that government is aware of the important role of the families on the rehabilitation of people with disabilities. It is expected that little by little all these institutions in the disability sector will develop adequate programs to respond not only to the needs of people with disabilities in terms of livelihood, but also by caring for their psychological well-being, within a framework that considers local cultural beliefs seriously.

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[9] Law on the Protection and the Promotion of the Rights of Persons with Disabilities. July 2009

Analyzing current support from the Government, Handicap International (Chrann & Corey-Boulet, 2009) recently reported on the problems faced by people with disabilities with regard to pensions. According to this report, people with disabilities often receive their pension late or have to bribe the officials to have the monies released. Many are forced to sell their entitlement to a pension to solve an unexpected and urgent household problem. The report recommends that government carefully monitor its programs regarding government funds, pensions, or economic incentives to avoid corrupt practices becoming a barrier to access for people with disabilities.

Furthermore, in order to integrate persons with disabilities into the social environment and increase interaction with other people, MoEYS has begun to implement the Policy on the Education of Children with Disabilities and its Master Plan. While the Master Plan does provide for specialized courses to be developed, including a special education course to train teachers to work with children with intellectual disabilities, this course is yet to be developed and taught. As more training is provided, and staff gets a better understanding of intellectual disability, they will be able to identify new beneficiaries. This capacity of identification will benefit directly those children with mild levels of intellectual disability, which are the most overlooked group (see Carter 2009).

CHAPTER 3
Cultural Perceptions of Intellectual Disability

This chapter analyses the perceptions and attitudes towards people with disabilities in Cambodia expressed through (a) language and (b) religious beliefs. The first section examines both the usage and the cultural meaning of terms used to describe people with disabilities and the effects of the cultural meaning of the language of disability on parents' help-seeking behavior. The second section examines historical and contemporary responses to people with disabilities that are strongly tied to the tenets of Buddhism, the predominant religion in Cambodia.

3.1 The Language of Disability

Advocates and self-advocates alike in the disability field have argued that perceptions towards people with disabilities are strongly affected by the words used to address or describe them, whereby derogatory or demeaning terms tend to perpetuate negative attitudes while positive or value-neutral descriptors can generate more respectful, accepting attitudes. The language of disability is deeply entrenched in the culture, in terms of usage and meaning[10].

3.1.1 Usage of the language of disability

In the Cambodian socio-cultural context, there are different words used to describe what English speakers call "disability". For example, ពិការ [*Pikar*], in general, most people will use to refer only to people with a physical disability, such as ពិការដៃជើង ([*Pikar Dai Chung*] - those who have lost a limb) or ពិការភ្នែក ([*Pikar Phneak*] – blind). However, the word គ [*Kor*] rather than ពិការ [*Pikar*] is used for people that cannot speak to refer to their speech difficulties. ថ្លង់ [*Tlorng*] is a word used to refer a person with hearing difficulties, while ឡប់ សតិមិនល្អ មិនគ្រប់ទឹក វង្វេង [*Lop, Saati Man Loho, Man Krup Teuk, Vongveng*] are used for people with some kind of intellectual disability.

Recently, scholars and people working in the sector of intellectual disability have started to use more neutral terms, such as: ពិការខួរក្បាល ([*Pikar Khuo Kbal*] - Brain with disability), មានបញ្ហាខាងសតិបញ្ញា ([*Mien Pañeja Khang Sati Paññaa*] - Have problem related to mind's intellect), កំសោយបញ្ញា [*Komsaoy Paññaa*] or បញ្ញាអន់ [*Paññaa On*]

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[10] For instance, the term "mental retardation" has such negative connotations in the US because of the derogatory use of the term "retard" that in 2010, the US government amended its laws to replace all references to this term with "developmental disabilities".

(weak or poor intellect). These terms are intended to replace the popular words that disability advocates consider are offensive appellatives which discriminate against people with disabilities. Unfortunately, the offensive words continue to be used in the daily vernacular lexicon of Cambodian people[11].

3.1.2 Cultural meanings of the language of disability and their effects on parents' help-seeking behavior

In addition to the derogatory connotations implied in certain words, the meaning of terms to describe specific conditions also has significant implications for attribution of cause and, therefore, for parents' help-seeking behavior. For instance, our study found that many parents associated symptoms such as the convulsions in epilepsy or the uncoordinated movements of cerebral palsy with the presence of a malevolent spirit. Australian researcher Eisenbruch (1992) notes, in the case of epilepsy, this evil spirit causes the symptomatic presentation of convulsions called ឆ្កួតជ្រូក [*Chhkuot Chruk*]. The term *Chhkuot Chruk* is the combination of two words, *Chhkuot* which means madness or serious sickness whereby patients cannot control themselves, and *Chruk* which means pig, and refers to the sounds provoked by the convulsion which are similar of those produced by a pig.

Another word typically used to describe epilepsy, nerve paralysis, and meningitis is ស្កន្ធម្ដាយដើម [*Skon Mday Deum*] which literally means "evil spirit of one's previous mother". The whole phrase taken together means the attempt of the newborn's previous mother in the form of an evil spirit to take back the child that she lost through an unfortunate event. The reasons why these spirits can cause damage are several, since spirits are opportunistic and are constantly waiting for the right moment and place to attack vulnerable victims. For instance, people believe that a newborn has a space between the brain and skull into which a spirit could fit and cause misbehavior.

Eisenbruch (1992, cited in Ovesen and Trankell, 2010) found that, although these terms are used by traditional healers and modern doctors alike for similar conditions, for instance *Chhkuot Chruk* to describe convulsions caused by epilepsy, the *cultural* meaning of the term is far different from its meaning in western or modern medicine. As a result, health workers in hospitals and traditional healers in communities will treat the same condition very differently[12]. His study found that there are 12 kinds of *Skon*, of which *Skon Mday Deum* is only one, and that some traditional healers, having developed the capacity to recognize these different types of *Skon*, are capable of providing specific treatment according to the characteristics presented in the patient. The spirit of the previous mother

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[11] In India, too, for instance, the formal but less well-known term "vikhlang" (disabled) was introduced in the early 1970s to replace commonly used but derogatory descriptors for people with disabilities like "pagal" (mad) or "langda" (lame). Over time, with government-mandated regular media coverage on people with disabilities, use of the formal term has become much more widespread even in street and conversational language (Kalyanpur, 2007).

[12] A study of Hmong beliefs about epilepsy by Anne Fadiman (1997) also found attribution of spiritual causes. For instance, the Hmong term for epilepsy is "quag dab peg" which literally means "the spirit catches you and you fall down". The book is a vivid description of the conflict between the Western and Hmong viewpoints. Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors and the collision of two cultures*. New York: Farrar, Straus & Giroux.

is represented by different kinds animals (dog, tiger, monkey and owl) that try to cause the death of the child in order to take her/his spirit to live with her.

If the *Skon* is caused by a dog, the child will have convulsions and pain in the right side. The treatment in this case should be done through a ritual composed by a series of blowing and spraying water across the body from the left to right side. If the *Skon* is caused by a tiger, the child will suffer abdominal pain and shake in the limbs. In this case, treatment should be done along the body from above to down and the same with the body turned upside down. When the *Skon* is caused by a monkey, the child will have left-sided symptoms. The treatment should be done from below up to the head. And finally, if the *Skon* is caused by a bird, the child will experience left-shoulder pain and trembling. Treatment should be done from below until the upper part of the head. In all the treatments, the ritual starts on the opposite side of the attack to relieve the attacked side with the healing properties of the healthy side or the side that is unhurt by the bad spirits:

> *"Kru Khmer [traditional healer] may burn the patient's skin at certain points on his body with cotton wick or pith. Pigs always use their snouts, and their demeanor is like that of the patient with Chhkuot Chruk. Burning the patient's nose while he is convulsing may be useful in making the patient regain consciousness, but the point at which it is applied also has symbolic meaning. People with Chhkuot Chruk have damaged Saa Say [nerves] because their junctions inside the brain have been burned, and there is a damaged connection with the lungs and heart; so the Kru burns the tip of the nose where the Saa Say meet. The Kru say that the burning threatens the cause of Chhkuot Chruk which no longer dared to menace the patient. In performing such transformation rituals, the kru use a complex ritual, using Yantra (amulet), Mantra, blowing, spraying, and pouring lustral water, and administering medicines." (Eisenbruch, 1992)*

Our study corroborates Eisenbruch's findings. Some of the parents we interviewed who were in search of the "real" causes of disability explained the situation within their own cultural parameters, also believing, for instance, that the cause of epilepsy reflected the connection between the preceding lives of the newborn child and the spirit of a previous mother. Because of this attribution of spiritual causes to several conditions, such as epilepsy and cerebral palsy, parents would take their child to the traditional healer *[Kru Khmer* or *Chool Rup]* rather than to the hospital. Acknowledging that conventional medicines could relieve the symptoms but not remove the cause,parents would request a special ceremony, where religion and magic were mixed to get out the *Skon,* or what they perceived as the cause, from the child.

Even parents who did seek treatment with doctors in hospitals, once they realized that their child's chances for improvement were no better than before, would try the traditional ways. Therefore, some mothers looked for help among the most reliable traditional healer for the family or community. Our study found this to be a frequent trend among the parents although this help-seeking behavior does not preclude a visit to a conventional doctor at the same time or after.

> *"Vinh was so different from other children I knew before, he was very silent since his birth, he never cried. His eyes were closed until he was one month old. I was very worried and wondered about my child's condition. Once he was sick, and I was really worried, then I brought him to the Kru Khmer to know once and for all what was happening with my child. The Kru told me that my child was suffering from Cerebral Palsy (ស្កន់ [Skon]) and then, he started to recite incantations and blowing potions (ផ្លុំស្ដោះ [Phlom Sdos]) on my child's body[13]. I kept going to see him at least 3 times, but since there was no change I decided to look for another, and then another. One day finally I followed somebody's advice and I brought my baby to the hospital" (case study 7).*

> *"Since Chiva was born, I noticed that she cried very frequently, different from other babies. I didn't know why, but when I asked to my mother and other neighbors, they assumed that Chiva had epilepsy [Skon] and they advised me to take my child to the Khmer traditional healer [Kru Khmer]. Thus I decided to take Chiva to the Khmer traditional healer. In total, I brought Chiva to 6 Khmer traditional healers, both inside and outside the village. All the results failed, my child did not get better. Moreover, I spent much money with bad results, I really could not afford anymore." (Case study 1)*

> *At the age of three months, Pisey got fever and then I brought her to consult with a Kru Khmer (traditional healer). The traditional healer told me that Pisey had Skon Mday Deum (epilepsy), and that he needed to Sdos her (to blow potion on her). Pisey spent around one month with the traditional healer but her disease could not be cured. Some elders told me that probably the problem was not related with Skon Mday Deum. It that had been the problem, one month should have been enough. Therefore, they suggested that I bring Pisey to the hospital. Then I decided to bring her to Kantha Bopha hospital in Phnom Penh, where I learned that it was too late to bring my child, as permanent damage was already done. Pisey did not recover completely but at least she did not die. (Case study 3)*

3.2 Religious Beliefs and Perceptions of Disability

Originally established as a Hindu empire which built the magnificent temples of Angkor Wat, the Khmer civilization converted to Buddhism during the reign of Jayavarman VII in 1181-1215 (Chandler, 2000). Even today, 85% of the population is Buddhist -- Buddhism is the national religion – and many attitudes towards people with disabilities are entrenched in Buddhist beliefs, the most predominant being the principle of *Karma*, which explains that bad actions in an individual's previous life could affect the present or next

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[13] Treatment based on blowing a potion prepared by the traditional healer. This potion is composed of water, herbal medicines, and especial roots. This process of blowing is generally accompanied by rituals, which are a mixture of elements belonging to Brahmanism, traditional beliefs (animism), and Buddhism.

one. Animism, with its traditional beliefs in ancestors and sprits, is also strongly present in the daily life of Cambodians.

3.2.1 Perceptions of disability in antiquity

From traditional folklore, it is possible to glean information on how Cambodian people have, through the ages, perceived/defined people with disabilities. These tales provide an interesting insight into the social status of people with disabilities: they were considered the lowest part of the society, even as their importance and value for society were being recognized.

Here we narrate, in its entirety, one Buddhist folktale that illustrates this ambivalence in perceptions: the story of the crippled and mute prince Temiya which gives us an idea of the meaning and value of a person with disabilities. In this story, disability seems to be incompatible with societal expectations wherein each member is required to fulfill their position with a specific duty, and might lead to the elimination of the individual. However, in another interpretation, it could also be argued that people with disabilities are regarded as an important part of the society because they remind us of the fragility of humankind[14].

> *There lived a king of Benares who, despite all his riches and plenty, still was unhappy. Though he had sixteen thousand wives, he had no son or daughter. Each of his wives prayed that she might bear a son to him. His main queen, Chendadevi, asked of the great god Sakka: "If through my life I have done only good, let a son be born to me." When her plea reached Tavatimsa heaven, the throne of Sakka, king of the gods, became warm, a sign of an injustice on earth. Sakka realized that he had overlooked the virtues of Queen Chendadevi. Immediately, from among the deities in heaven he chose the Bodhisattva, who he knew would serve as a model of self-denial for the kingdom of Benares, and sent him down to earth to be conceived in the queen's womb. In addition, to five hundred noblemen's wives he sent five hundred more beings to be born as the Bodhisattva's attendants. When the queen felt as though her womb contained a diamond, she knew she was pregnant. She informed the king, and both were happy. Great care was taken until the day of her delivery. Upon hearing the words of the birth of his son, the new father felt paternal affection lighten his heart. At the same time, five hundred noblewomen gave birth to infants who were to grow up with the Bodhisattva and serve him. The Bodhisattva was given sweet milk from sixty-four wet nurses selected for their flawless beauty. After presenting the nurses to the queen the king felt generous and told her he would grant her anything she asked. However, the queen postponed her request, as she preferred to wait for the day when she might need it.*
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> *On the occasion of the naming of the child, the Brahmins proclaimed that the royal son and heir to the throne possessed every mark of good fortune. The king named his son Temiya-Kumaro, meaning 'prince drenched with water', because both his birth and the day on which he was born had been very wet. When Temiya was only one month old, he was dressed up for his first public appearance and brought to the throne of his father to sit on his knee. Many courtiers admired his beauty and murmured their approval. Four robbers were then brought before the king to be judged. Temiya witnessed his father sentence one*

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[14] These are just two possible interpretations that our research team developed. Further research may identify other interpretations.

robber to a thousand strokes from thorn-baited whips, another to imprisonment in chains, a third to death by the spear, and a fourth to death by impaling. The infant Bodhisattva was terrified at his father's apparent cruelty and thought to himself, "A king acts as judge, and so he must perform cruel actions every day. By condemning men to death or torture, he will however himself be condemned to hell." The next day, awakening from a short nap and looking up at the great white umbrella above him, the infant began to think of what it would mean to be king. These thoughts alarmed him, even more so as he remembered a previous existence in which he himself had reigned as king of Benares for twenty years. As a result of dread decisions forced upon him in the position of king, he had had to suffer eighty thousand years in hell. Now he was destined to become king again in the same city, again to suffer the same fate. This was more than he could bear. As he wondered if escape was possible, a goddess dwelling in the umbrella above him, who had been his mother in a former life, spoke to him "Temi, my child, let me help you. You must do as I advise: Pretend to be a crippled mute. Don't move your limbs or use your voice. Then the people will refuse to crown you king and you shall be free." The Bodhisattva at once began to show signs of being different from the other five hundred children. While the others cried out for their milk, Temiya did not utter a sound. For the first year, his mother and nurses noticed with alarm that he neither cried, slept moved nor listened, though his body appeared normal. Knowing that he must feel hunger, they tried to force a sound from him by withholding his milk, at times by starving him for a whole day, but to no avail. In his second year, they tempted him with various cakes and sweets over which the other children fought. But Temiya would say to himself: "Eat the cakes if you wish for hell", and thus abstained. All kinds of foods, fruits, and toys left him unmoved, though other children grabbed greedily for them.

When he was five, they tried to terrify him into speaking. He was placed in the center of a house thatched with palm leaves. A servant was then ordered to set fire to it. Where normal children would have run away shrieking, the Bodhisattva remained motionless and sat quietly as the fire came closer to him, until he was taken away by his attendants. At six, they let an elephant loose at him; at seven, they allowed serpents to coil about him. Still he remained unharmed and unmoved. In the following years, they showed him terrifying mimes, threatened him with swords, and made holes in four sides of a curtain around his bed and had conch players blast their sound through to him. They tried him with drums and sudden bright lamps in the middle of the night, but they failed to break his trance. Desperate, they covered him with molasses and allowed flies to cover and bite him, but he did not flinch. They forced him to remain unbathed, but his need for cleanliness did not overpower him. Pans of fire were placed under his bed, causing boils to break out on his body, but still he said to himself that hell was a hundred thousand times worse. His parents besought him to speak, to move, to listen, but he dared not. At sixteen, when he would have been named heir apparent, they led him to a perfumed chamber and tried to tempt him with beautiful maidens, but he stopped himself from breathing in order not to be weakened by the fragrances. At last, the king summoned the soothsayers and asked them why at his son's birth they had not mentioned any threatening signs of this affliction. Not understanding Temiya's behavior but unwilling to admit their ignorance, they explained that they had not dared cast a shadow on the king's joy when, after so many years, he had been given a son. But now, fearing for the safety of the country should an apparent idiot be named heir to the throne, they predicted dangers to the king's life if Temiya were allowed to remain in the kingdom. Alerted by their words, the king asked what he should *do. They advised him in this way: "You must yoke some horses to a chariot, send your son away in it, passing by the western gate, to a graveyard, and there he must be buried."*

When the queen heard of this plot, she knew the time had come to make the request which the king had promised years ago to grant. "Give the kingdom to my son", she demanded. " Once he is crowned, he will certainly speak." The king protested. "Impossible, my Queen, for your son brings ill luck to us." "Then give it to him for seven years", she responded. Again the king refused. "Then for seven months", she pleaded. "O Queen", he said, "I dare not." "Then, alas, for seven days," she sighed. "Very well," the king relented. "Your wish is granted."

And so it happened that Temiya was given the kingdom for seven days. He was led around the city, sometimes on an elephant, sometimes on men's shoulders. Still he would not move either his limbs or his lips. On the seventh day, his mother begged him to speak, for on that day he was condemned to die. The Bodhisattva gravely considered her request, thinking to himself: "If I do not break my silence, my mother's own heart will break; if I do, I shall have wasted in one second what efforts I have made for sixteen years. Moreover, if I keep my pledge, my parents and I shall be saved from hell." Thus, Temiya again decided to be patient, for the day was near when he would be freed from the fear of inheriting the throne, and on that day, he would be able to speak. As the next morning dawned, the king gave his final orders to Sunanda the charioteer. "Yoke some horses to a chariot and set the prince in it. Take him out the western gate and find some ground in which to dig a grave. After you have dug the hole, throw him into it and break his head with the back of your spade to kill him. Then scatter dust over him and make a heap of earth above. After bathing yourself, come back here."

The Temiya Jataka -Temiya proves his own strength by lifting a chariot.

Source: Mural Painting in Vihear Sour Pagoda,
Oudong Commune, Kompong Speu Province (Cambodia)

Sunanda took Temiya off, but though he thought he was passing through the western gate, the Death Gate, he did in fact drive to the eastern gate, which was the Victory Gate, and one of the chariot's wheels struck the threshold. At the sound, the Bodhisattva knew he was on the threshold of attaining his freedom. By the power of the gods, a graveyard

> *appeared. Sunanda stopped and removed Temiya's royal ornaments from him, releasing him in one stroke from his yoke of royalty. The Bodhisattva was at last freed from his vow, and as Sunanda worked at digging the grave, Temiya thought to himself, "In sixteen years, I have never moved my hands or feet. Can I do so now?" Whereupon he rose, rubbed his hands together, rubbed his feet with his hands, and alighted onto the ground, which at his touch became like a cushion filled with air. He then exercised his limbs by walking back and forth until he was satisfied that he had the strength he thought he had lost.*
>
> *This was his only chance to escape kingship and enter the forest as an ascetic, and the Bodhisattva wondered, was he powerful enough to overcome Sunanda if he tried to prevent his escape? As a final test of his strength, the Bodhisattva seized the back of the chariot and lifted it high with one hand as if it were a toy cart. Indeed, his power was confirmed. He walked over to the charioteer and tried to jolt him into looking at him with these words: "Behold the man you seek to kill, not deaf nor dumb nor lame. Stop or bear the wrath of hell, for by this act you'll die".*
>
> *Sunanda looked up but was so dazzled by the Bodhisattva's beauty that he did not recognize him at first. Again Temiya identified himself. Suddenly Sunanda understood and fell at his feet, stammering that he would be honored to escort the prince home to inherit the kingdom. He who was destined for Buddhahood chided him, for nothing would deter him now from leading the pure meditative life. He described his previous existence and subsequent generations in hell and then ordered Sunanda to return to the palace immediately to tell his parents that he was still alive and thus spare them unnecessary grief over the loss of their only son. As the charioteer approached the palace alone, the queen, who had been waiting by a window, saw him, assumed that her son was dead, and began to weep. But when Sunanda told her his story, she ceased. The king was told what his son had done, and he and the queen set out at once for the Victory Gate, hoping to lure the prince home.*
>
> *When the long procession of horse-drawn carriages came to a halt, the royal pair found their son living in a hut of leaves prepared for him by Sakka. They saw that he had already put on an ascetic's garments of red bark and leopard skin, a black antelope skin over one shoulder and a carrying pole over the other. His hair was tied up and matted, and he held a walking staff in one hand. Temiya welcomed them and explained to them the reasons for his sixteen years of self-denial. In awe of their son, they no longer begged him to wear the crown but were themselves inspired to embrace the holy life. Returning to the palace, the king ordered the royal treasure jars to be opened and the gold to be scattered about like sand. Sakka built for the entire kingdom a hermitage three leagues long, so that all who aspired to Nirvana could partake of the meditative life.*

People with disabilities feature as central characters in other traditional folktales as well. The Buddhist tale, *"Neang Badachha"* ("Miss Badachha"), tells the story of a woman who becomes ឡប់សតិ [*Lop Sati*] or ឆ្កួត [*Chhkuot*] (crazy) after the death of her beloved husband, children, and parents. After an encounter with Lord Buddha, she recovers and becomes a well-known female monk.

Another story, *"A Kvak A Kvin"* ("The Blind and the Crippled") describes how two people with disabilities save the king's daughter and other people from the cruelty of giants. At the end of the story, the men are not only rewarded by the king with a lot of gold but also recover from their disability. After their good deed, they are able to see and walk like non-disabled people.

It is significant that, in all these stories, the central characters recover from their disabling condition. A clear underlying message is the undesirability of disability and the necessity of being cured, of undergoing a process of transformation from being disabled into "normal" people before they can be accepted within society.

3.2.2 Perceptions of disability in contemporary Cambodia

Scholars in the field of anthropology assert that most societies consider intellectual disability an anomaly and will approach it in two ways: negative responses, the most common, which render the anomaly invisible, denied, and condemned, while positive responses "*recognize the anomaly and try to reorder our pattern of reality in order to accommodate it, perhaps leading to a paradigm shift in classificatory values"* (Bowie, 2002).

An anthropological study by Douglas (1976, cited in Bowie, 2002) about the body as symbol identified various negative responses to dealing with these anomalies, six of which match responses that emerged from our cases studies. For example:

- *Elimination of the anomaly through physical control*, so that whatever threatens the social stratification must be eliminated. In our study, we found that, in traditional tales and contemporary history, intellectual disability was barely recognized compared to physical disability. Although people with physical disabilities were in the lowest stratum of society, they are included more and more in contemporary social life.
- *Avoidance of the anomaly*: there may be taboos or rules prohibiting contact with an anomalous person. Our study found that this strategy is very common in Cambodian rural areas. Children with intellectual disabilities are frequently hidden by the parents inside the house, and are not welcome at traditional ceremonies because of the belief that the presence of a person with disabilities at such an event could affect the sanctity of the ceremony, create conflict in the lives of the new couple, or increase their chance of having a child with disabilities in the future. Pregnant women are advised to display pictures of beautiful children in their bedrooms and avoid any contact with people with disabilities because of the belief that the child they are expecting could get some kind of imperfection or disability. Scottish social anthropologist Sir James Frazer posited the theory of "contagious magic" to explain people's belief that things or persons once in contact with others can afterwards influence each other. This behavior is reinforced by the Buddhist belief of *Karma.* In other words, a person with disabilities who has bad *Karma* is perceived to be able to transmit this to others and render them vulnerable. Similarly, Buddhist monks will not visit the homes of people with disabilities and people with disabilities are not brought to the pagoda. According to Buddhism, monkhood is considered one of the most important ways to gain merits, therefore being in contact with bad *Karma* may reduce one's chances for a rebirth with better status or the possibility to be released from the cycle of rebirth. This belief leads to social exclusion.

- *Anomaly may be labeled dangerous*: because so little is known about the causes of intellectual disabilities, particularly those that manifest anomalous behaviors, such as autism and hyperactivity, and about strategies for dealing with them, the general belief in rural communities is that the child may be dangerous and able to “contaminate” others.
- *Anomaly can be elevated through ritual*: when the corporeal aspect of the anomaly cannot be treated or cured through traditional remedies and simple rituals, the traditional healer will perform a ritual of reconciliation within the realm of the spirits. In Cambodia, traditional healers are charged with the responsibility of dealing with other realms and supernatural beings that could be attempting an attack against the life of the individual or the family. Through this process of ritualizing the disability, families are comforted by the knowledge of the origin of the condition, as the first step towards acceptance.
- *Anomalies as source of humor:* perhaps the most common approach to disability, when other children tease and give nicknames to those with some impairment. In our study, we observed this occurring not only among other children but also among adults and members of the same family.
- *Anomaly can be redefined* when the birth of a child with disabilities may seem to threaten the dividing line between human and non-human. For example, in the case of the Nuer in Sudan, a child with disabilities is seen as a monster accidentally born to human parents, and the child is redefined as a hippopotamus. This reclassification provides the rationale for returning "the baby hippopotamus" to its natural habitat, in this case the river. In the Cambodian context, the term *Neak Pikar* literally means “Transformed Person”. Other redefinitions are more offensive, such as ឆ្កួតជ្រូក [*Chhkuot Chruk*] or mad pig.

Douglas also identifies a positive reaction which involves *redrawing the classificatory boundaries in order to incorporate the anomaly.* This is a process that occurs continually, either publicly, through legal contests and organized protests, or quietly and without controversy. In the case of Cambodia, this is a process that has been started by the work of NGOs and backed by law.

Additional examples of positive reactions and redrawing include Cambodian people with disabilities who have been able to achieve a successful life and become popular. One such person is Sandhor Mok, a famous poet in the court of King Norodom. Born in 1846, he became paralyzed after contracting a severe case of smallpox. He was educated in the pagoda, where he specialized in poetry, and later was married and had five children. Even now, Sandhor Mok is considered one of the greatest poets in Cambodia. His achievements have been praised by religious people and scholars. His extensive literary work includes critical poems against the French protectorate and his classic story, *Tum Teav,* which is very popular among Cambodians. Another famous contemporary artist is Kong Nay, a blind singer and player of *Chapei* (Cambodian two string guitar) whose talent has won him the love and popularity of Cambodian people. He is always welcomed to many special ceremonies during Khmer New Year. These two examples provide evidence that people with physical disabilities who have brought extraordinary contributions to society are eligible to reintegrate into society as full citizens. On the whole however, in contemporary Cambodian society, children with disabilities are generally considered to be undesirable, particularly at the family and community level.

3.3 Conclusion

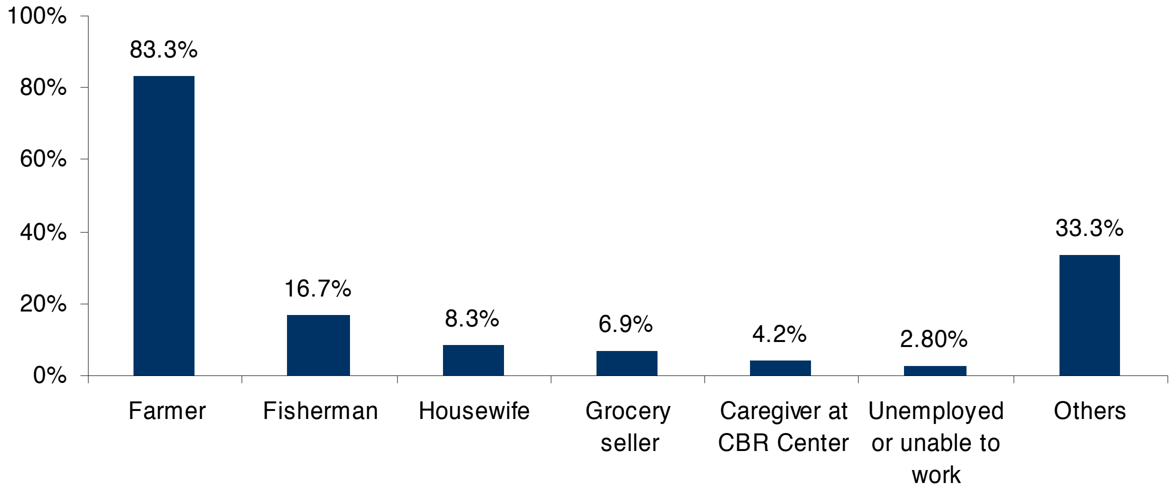
The examples of depictions of disability demonstrate the existence of a scale of values and social acceptance according to the type of disability. Thus, in this hierarchy, people with physical disabilities (motor, visual and hearing) seem to have a better chance of acquiring a higher social status than people with intellectual and mental disabilities (មនុស្សឡប់សតិ [*Monus Lop Sati*]). For example, deaf people have higher status than people with intellectual disabilities, because their physical restriction is less severe. People with physical disabilities are more likely to be rewarded and recognized within Cambodia society because they have the capacity to “overcome” their disability, as the traditional story of "The blind and the crippled" and the contemporary example of the blind *Chapei* player illustrate. On the other hand, individuals with intellectual disabilities are denied full acceptance in society as, for example, they are “not even able to get married”, an important indicator of a person’s capacity to fulfill their responsibilities within Cambodian society. However, it must be pointed out that, although people with physical disabilities may have more chances for social promotion, they are still discriminated against and continue to have less access to employment.

CHAPTER 4
Challenges Faced by Families

4.1 Socio-Economic Situation of Families with Children with Intellectual Disabilities

Analysis of the demographic characteristics of the participants in our survey (64 mothers and 8 fathers) indicates that 69 percent were married while 31 percent were widowed. Of the total surveyed, 40 percent have 1 to 3 children, while the other 40 percent have 4 to 6 children, and 20 percent of families have more than 6 children. The average family size is around 5 children per family, which corresponds somewhat with the 2008 National Census figures of 4.6 children per family for Kompong Chhnang province.. Of the 78 percent of our respondents who had attended school, 54 percent had completed primary school, 16 percent secondary school, and 1 percent high school, while 22 percent did not have any schooling.

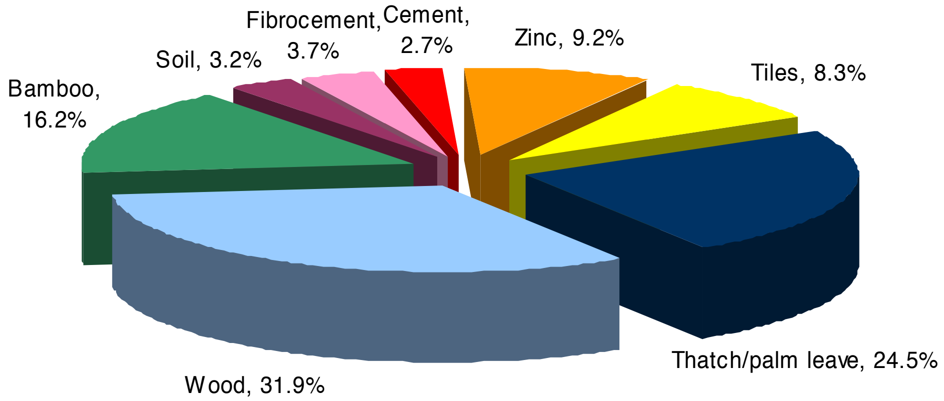
<u>Figure 3</u>: Parents' Current Occupations (n=72)



With regard to the economic activities of our 72 respondents, parent gave multiple responses (see Figure 3). The primary occupation for 83 percent of them was farming, and for 17 percent was fishing. Among the mothers, 8 percent worked at home, 7 percent sold small products in the market, and 4 percent were taking care of the child with disabilities. About 3 percent were unemployed because they were unable to work due to their own health condition. Some respondents (33%) were also engaged in other temporary activities to generate income like collecting firewood in the forest, collecting sugar palm juice, growing vegetables, and weaving bamboo baskets during the dry season, and farming or planting rice in the rainy season.

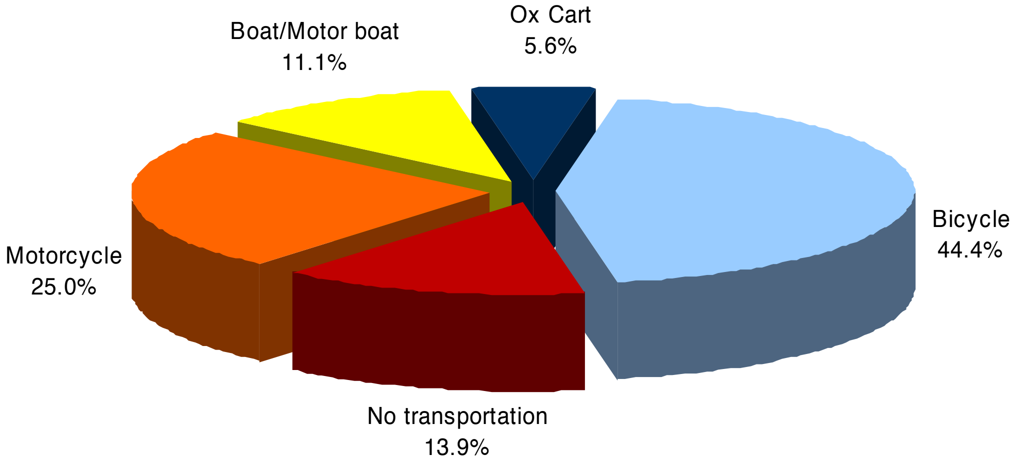
We used type of housing materials, means of transportation and the daily income generated by household as the main indicators of the socio-economic situation of our respondents (see Figure 4). We found that the majority of the respondents (72%) used inexpensive materials for house construction like low quality wood, palm leaves or thatch and bamboo. Some synthetic materials like fibrocement were also used, but to a much lesser extent.

Figure 4: Housing Materials (n=72)



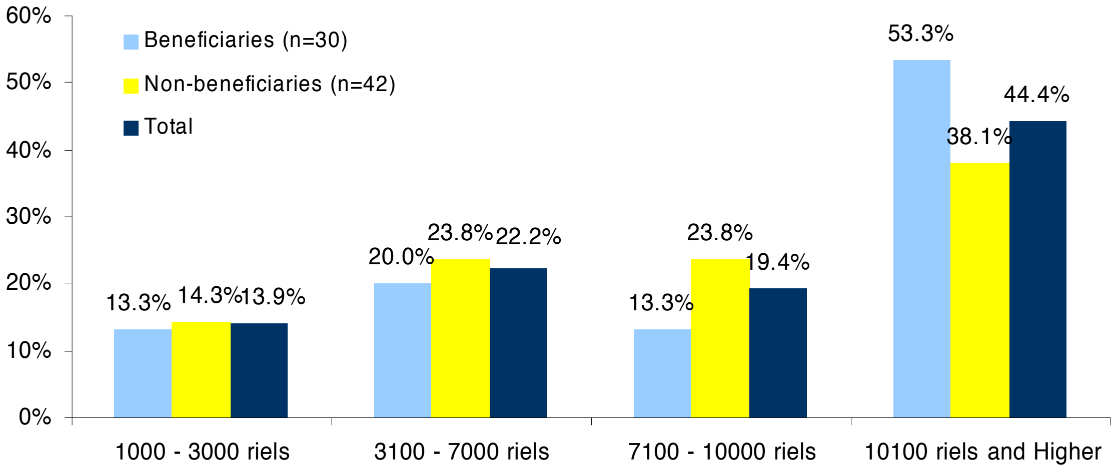
In terms of means of transportation (see Figure 5), most of the respondents (44%) used bicycles, 25 percent owned motorcycle — the most popular vehicle of transportation in Cambodian rural areas — while as many as 14 percent did not have any means of transportation. Of some of the respondents living in floating villages on Tonle Sap Lake, 11 percent named a boat as their primary mode of transportation.

Figure 5: Means of Transportation (n=72)



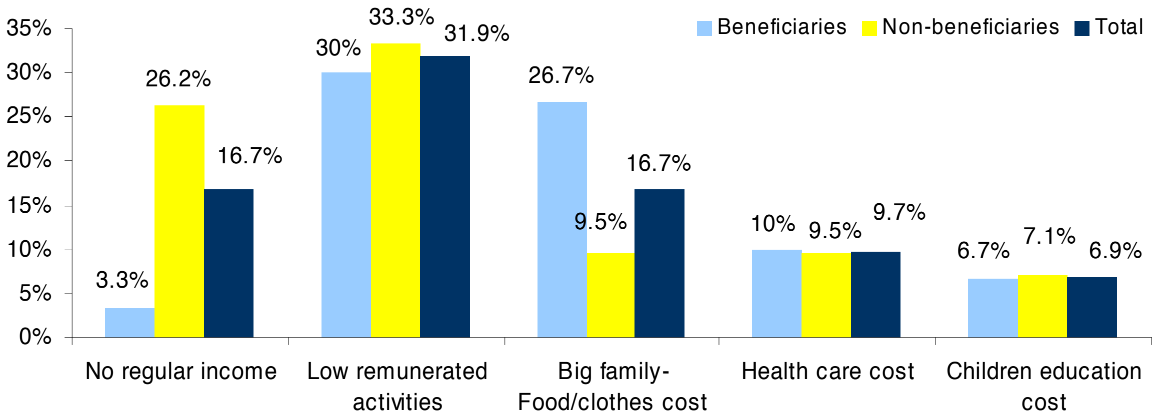
Although we did ask about daily income, previous research experiences have shown that this is not really a reliable source of information on families' economic situation, because of the variety of answers given by the villagers. In this research as well, we had some difficulty to learn about daily income, especially because the respondents did not have regular incomes and earned according to the agricultural or fishing season, or other seasonal activities. However, according to their own estimation, we established that 14 percent earned between 1000 – 3000 riels per day, 22 percent between 3,100 – 7,000 riels, 19 percent between 7100 – 10,000 riels, and finally 44 percent more than 10,000 riels a day (see Figure 6). There are some variants in terms of income between the two groups of beneficiaries and non-beneficiaries: 53 percent of beneficiaries generated more than 10,000 riels a day against only 38 percent of non-beneficiaries.

Figure 6: Daily Income (n=72)



We also asked respondents if the money they earned was sufficient for their needs (see Figure 7). Only 18 percent of the respondents replied that they had enough income to manage their daily expenditures, while the other 82 percent said that they had difficulties in covering daily basic needs. Among those families with difficulties, 17 percent attributed their economic problems to irregular incomes, 32 percent to low remunerated activities, 10 percent to health care costs, 7 percent to education costs, and 17 percent to problems due to the large number of family members.

Figure 7: Reasons for Insufficient Income (n=72)



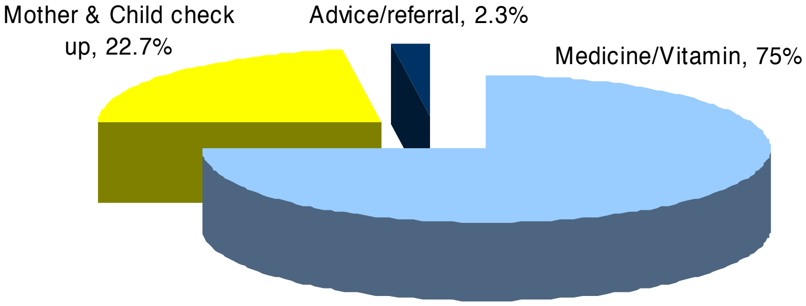
We found that "low remunerated activities" (i.e. activities generating an income equivalent to or less than one US dollar per day) was the most frequent answer among both groups. While the difference between the two groups on most responses is slight, there is the most discrepancy on their response to the option of "no regular income", in that only 3 percent of beneficiaries found this to be a problem but over 26 percent of non-beneficiaries identified this as a problem. This remarkable difference of 22.9% might be because families who send their child with disabilities to the CBR centers have more work mobility and therefore increased possibilities to obtain more regular income, whereas the non-beneficiary families had to arrange constantly to have at least one parent or family member to care for the child with disabilities which resulted in less income. For instance, in the statement below, one mother describes her family's difficulties in generating income before she was able to benefit from the services offered by the CBR center.

> *"For my husband and me, it was very difficult to look after her. Sometimes he beat me because of her. My husband was so tired and angry against me, because I didn't have time to help him to go to the rice field or do other works, because I had to look after Chiva all the time". (Case study 1)*

4.2 Antenatal Care and Delivery

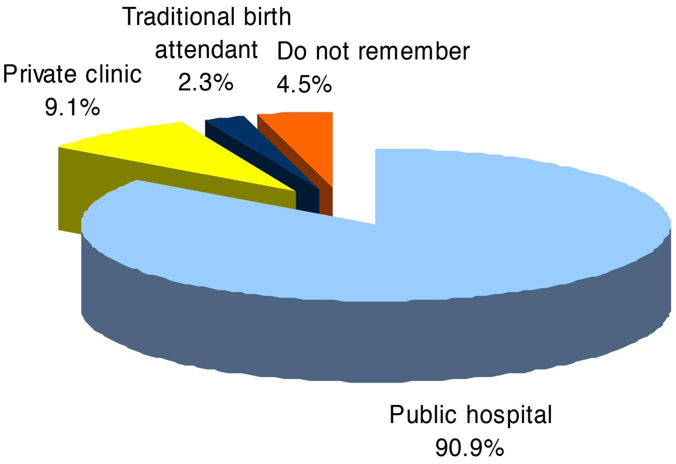
A noteworthy finding is that, despite the low income levels, 61 percent of the respondents, recognizing the importance of accessing health care during their pregnancy, attempted to look for and received some kind of antenatal care (see Figure 8). The service most frequently received (75%) was medicine prescription and vitamin supply. Less than 23 percent reported receiving a basic mother & child check-up, and only one mother reported receiving a referral to other health facility for further check-up. While the trend to seek antenatal care can be regarded as extremely positive, it appears that the range of services available is still limited.

Figure 8: Type of Service Received in the Health Care Facilities (n=44)



Among those who did not receive any kind of antenatal check-up, we found that there were various reasons that hindered antenatal care, including lack of health facilities near their homes, no money to pay consultation fees or to buy medicines. There were also some mothers who did not feel the need to go to the hospital for antenatal care.

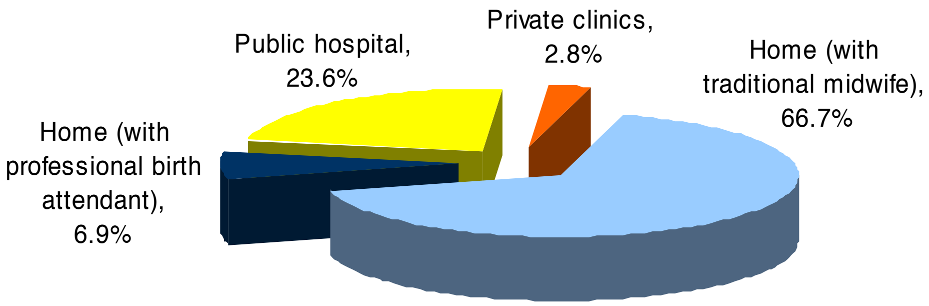
Figure 9: Place for Antenatal Care (ANC) (n=44)



The most popular place for seeking antenatal care was the public hospital (90.9%) followed by a private clinic (9%), while a small percentage (2.3%) went to see a traditional birth attendant. In 3 cases we had more than one answer, which mean that the mother went to two different places for ANC (see Figure 9).

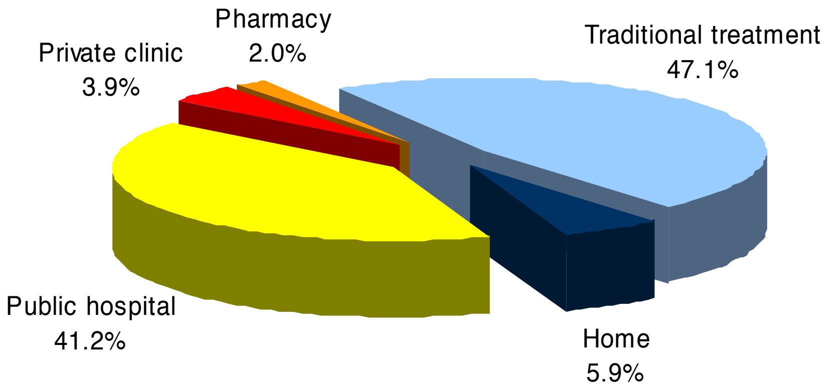
However, this trend was reversed at the time of delivery of the baby, when only 26.4 percent of the mothers delivered at a public hospital or private clinic, while the rest delivered their babies at home either with the help of a traditional midwife (66.7%) or a professional birth attendant (6.9%) (see Figure 10).

Figure 10: Place for Delivery (n=72)



In contrast to 39 percent of mothers who did not seek antenatal care, all the mothers sought postnatal health care (see Figure 11). Also in contrast to the small number of mothers (2.3%) who saw a traditional birth attendant for antenatal care, 47 percent of the mothers sought traditional postnatal treatment, with only 41 percent going to the public health care facilities (in contrast to the 94 percent who did so for antenatal care). Comparing antenatal and postnatal care, it is clear that the tendency is for women to go back to traditional practices for the latter.

Figure 11: Place for Postnatal Care (n=51)



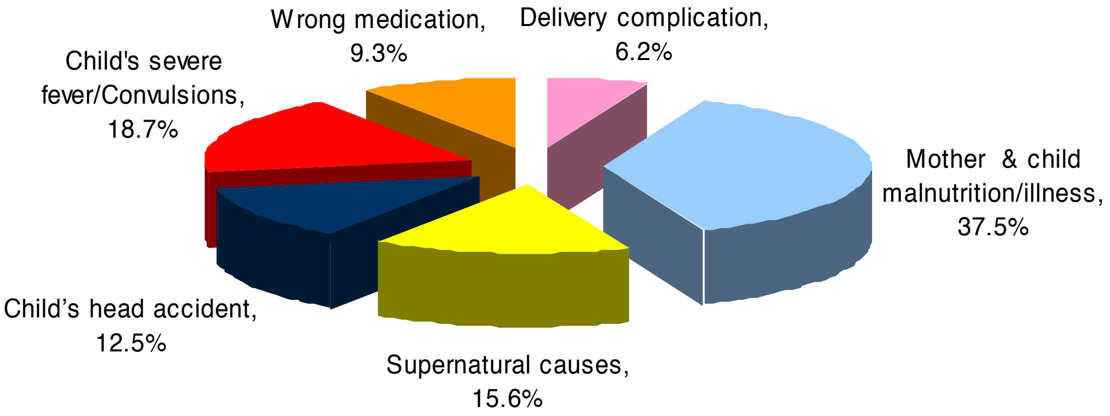
4.3 Parents' Perspectives on the Cause of Child's Intellectual Disability

When asked, 45 percent of the parents stated that they knew the cause of their child's disability. According to their perception, the cause for intellectual disability of their child was due to various factors, which we have divided into two types of responses: causes due to medical reasons and causes based in cultural beliefs. A longer analysis of disability causes based on cultural beliefs has been presented in the previous chapter. Here we focus on medically-based causes and briefly summarize the culturally-based causes.

4.3.1 Medically-based causes

Parents showed a high level of sophistication in their knowledge of medically-based causes of their child's intellectual disability. They identified various causes occurring during the different stages of pregnancy (antenatal, perinatal, and postnatal) including maternal malnutrition or illness, wrong medication, complications during delivery, child malnutrition, an accident to the head, or severe fever and convulsions. The most frequent (37%) cause of intellectual disability according to the parents' understanding was maternal and child malnutrition or some kind of maternal illness related also to severe malnutrition (see Figure 12). Research shows that severe malnutrition is indeed a cause of intellectual disability: maternal malnutrition can result in "intra-uterine growth retardation"[15] and while children's nutritional status in Cambodia has improved since 2005, child malnutrition continues to be a serious problem, affecting physical and intellectual growth (CDHS, 2010). Wrong medication during pregnancy was also mentioned as a possible cause of intellectual disability.

Figure 12: Parent's Understanding about Cause of Intellectual Disability (n=32)



Some parents identified a high frequency of severe fever as a cause for their child's disability. Another cause mentioned by the parents was head injuries due to an accidental fall. These causes are also supported by medical research. Finally, complications during delivery were pointed out as causing intellectual impairment, although parents were unable to clarify if the complications related to severe prematurity, very low birth weight, birth asphyxia or birth trauma.

During the in-depth interviews, the mothers provided further information on this topic. Some felt that their child's disability was the result of the mother having to work long hours

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[15] A study of causal factors for disability in children in urban slums in India found that the highest rates of handicap come from infants who are born at term but are low birth weight as a result of nutritional insult during pregnancy. Referred to as "intra-uterine growth retardation (IUGR)" infants, this group comprise 30-40% of the population of infants born in slums and, unlike premature babies, have relatively low mortality rates and are at greatest risk for developmental delays. Persha, A.J., & Rao, V.R.P.S. (2003). *Early intervention to intra-uterine growth retardation (IUGR) children at risk for developmental delay*. Secunderabad, India: National Institute for the Mentally Handicapped.

at home and in the rice fields, transplanting or harvesting, throughout their pregnancy and even up to a few days before the delivery, and having to resume their work only a few days later. One mother stated that her husband's alcohol problems had led him to beat her during her pregnancy and had left no money to buy food, as a result of which she gradually became weak and malnourished, while another mother said her severe malnourishment during her pregnancy had caused their baby's convulsions at birth. Again, research indicates that long hours of hard manual labor without adequate food, coupled with frequent pregnancies, can severely deplete a woman's nutritional resources and affect uterine growth (Persha and Rao, 2003).

Two mothers also mentioned, during the interviews, that probable causes the doctors had mentioned to them included the misuse and overuse of medicines during pregnancy, lack of hygienic conditions during the birth, delayed referral for their sick baby/child to the hospital, and congenital or genetic problems.

4.3.2 Culturally-based causes

About 16 percent of the parents also presented explanations for their child's condition that were culturally-based, attributing the disability to supernatural intervention. In one situation, the mother and neighbors of a child who had regular convulsions believed that the convulsions were the result of an accident in the child's previous life. According to the mother, the soul of a boy in the village who had previously been killed by a lightning strike, entered into her dream and asked her to become his mother.

In other cases, as mentioned earlier, *Karma* is sometimes used to interpret why people experience some kind of disability. According to Betsy VanLeit et al.[16], of the total 500 households they interviewed in Siem Reap and Takeo, at least 10 percent believed that one of the causes of disability was *Karma*. In this study as well, some mothers mentioned *Karma* as one possible cause of their child's condition.

Another cause of the attack could be also low fortune/luck (រាសីទាប ឬ ស្រុតចុះ [*Riesey Tieb* or *Srot Chos*]) that makes an individual vulnerable to or at risk of a spirit's attack.

4.4 Early Detection and Help-Seeking Behavior

The survey found that all the parents noticed and recognized early on the external manifestations of the child's condition, such as trembling, losing consciousness, weakness, or regular high fever, as well as physical abnormality (difficulties in mobility, limbs becoming smaller or shrinking, slower growth, uncoordinated movements, and convulsions) and communication problems, but most (75%) did not recognize these symptoms as possible precursors to an intellectual disability (see Figure 13).

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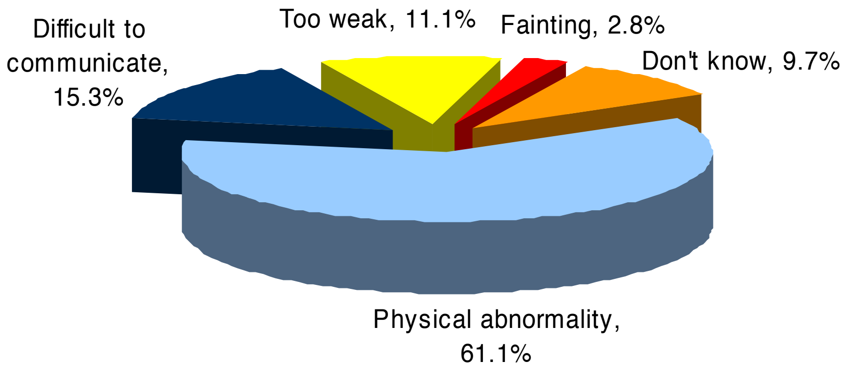
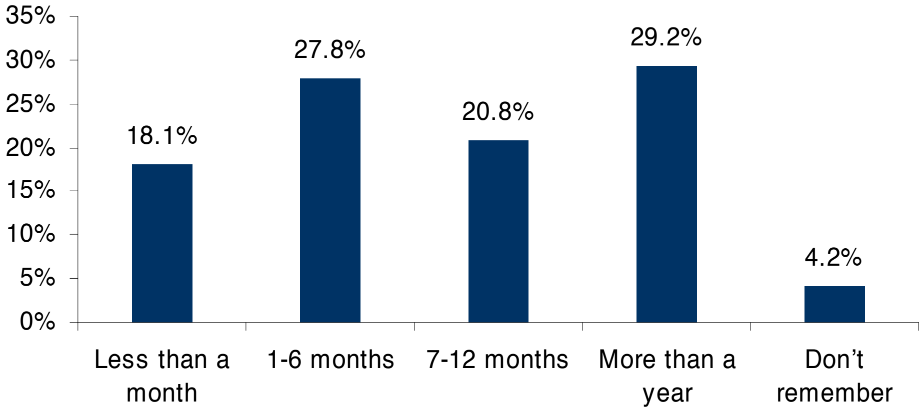
[16] Betsy VanLeit, 2008: Using the ICF to address needs of people with disabilities in international development: Cambodian case study.

Figure 13: **Difficulties Noticed by Parents (n=72)**



As many as 67 percent of parents noticed some differences in their child by the time the child was less or one year old; of this, 18 percent noticed something when their child was less than one month old (see Figure 14). While it may be that these parents were particularly observant in noticing these symptoms at such an early age, it is more likely that the severity of the disability meant that the symptoms manifested themselves at a very young age. However, we cannot ascertain this correlation between the severity of the disability and the parents' early identification from the data.

Figure 14: **Time Taken by Parents to Detect the Impairment of their Child (n=72)**



For instance, some months after the delivery, Chiva's mother, Ry, noticed that her baby *"used to cry too much and her head looked too small*". Describing her first impressions of Chiva, Ry said:

> *"I noticed that my child could not see and recognize others and she often raised her head and closed her hand. Her behavior made me feel that she was very different from other children; however, I did not understand exactly about her kind of problem and it made me unhappy. My husband and I thought that this problem maybe was caused from my delivery, but I was not sure about this. The [neighbors] mentioned that Chiva had become like this because I took pills for birth spacing but I told them that I never use it. They also said that I should not be taking care of her, and if Chiva died [it would] be better than her being alive, because then she would not make my life more difficult. (Case study 1)*

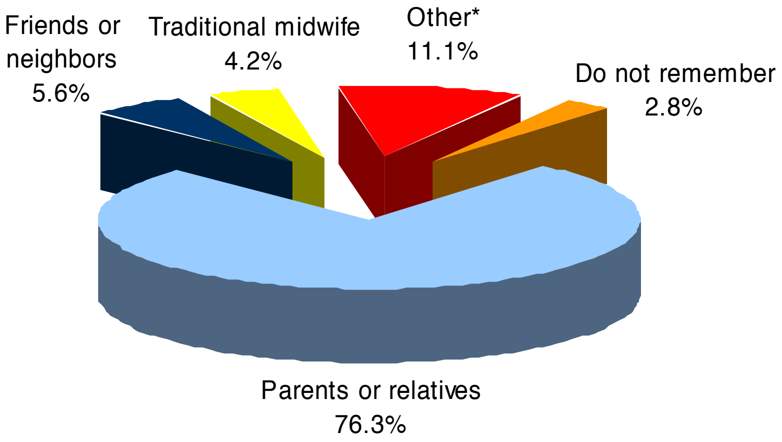
It was only when a few months later a neighbor suggested that she take her daughter to see a traditional healer that she acted on her fears.

It is not surprising that parents did not connect the symptoms as warning signs for developmental delay. None of the public school teachers and local authorities was able to do so either. New Humanity's preschool staff fared slightly better on these questions, largely because they had received some basic training on basic health care and disability issues. Finally, the special needs teachers at New Humanity's CBR centers had the most accurate answers in terms of disability identification, prevention, and treatment for specific cases they had worked with, having received advanced training on these topics and experienced some specific cases.

This variation and gap of basic knowledge on intellectual disability among the groups suggests the need for dissemination of information towards successful implementation of the inclusion and integration process mandated within Articles 9 and 16 of the *Law on Protection and Promotion of the Rights of Persons with Disabilities*.

In most of the cases (76%) parents or close relatives were the first ones to notice some difficulties in the child's development and behavior (see Figure 15).

Figure 15: Who Noticed the Child's Disability (n=72)

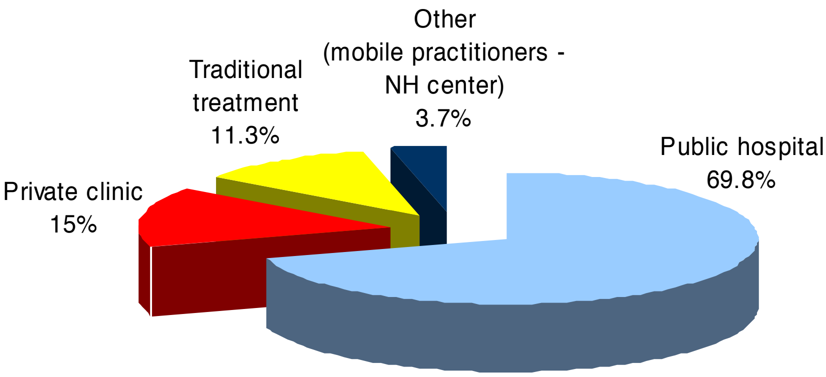


* Medical Doctor, NH staff

On observing these unusual symptoms in their child, most parents (74%) sought health care from both modern and traditional treatment. Almost 70 percent of this group brought their child to a public hospital, 15 percent to private clinics, 11 percent to a traditional healer (*Kru Khmer),* while 4 percent met other health care facilitators like mobile practitioners and NH staff. Almost 26 percent of parents (or 1 out of 4) did not seek any treatment for their child (see Figure 16).

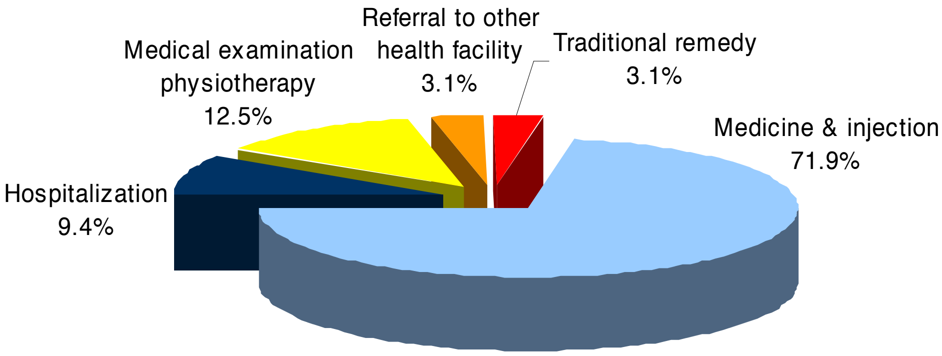
When parents were asked if the health providers where they sought help were able to recognize the type of disability affecting their child, over half of them (51%) answered in the negative. Although almost as many thought that the health providers were able to put the symptoms together to identify or name the impairment, it is evident that there are few health providers, especially in rural areas, who were adequately trained to deal with patients who may have an intellectual disability. Therefore, it is clear that there is a great necessity for training on this sector at provincial level, by building the capacity of a small team of people who can provide more accurate diagnoses and give appropriate treatment and follow up.

Figure 16: **Place Sought by Parents for First Treatment (n=53)**



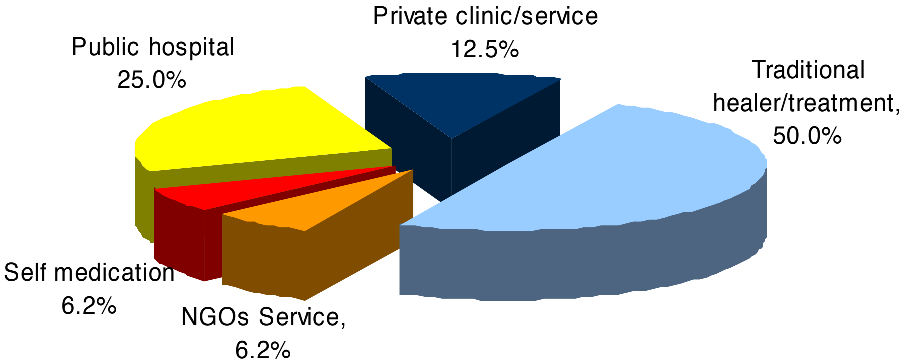
Among the parents who brought their child to a public hospital, private facilities or traditional healer, 60 percent of them acknowledged receiving some kind of treatment (see Figure 17). The treatment received was, in most cases (72%), a prescription of some medicines (pills and injections). In very few cases, children received further or more in-depth examinations, and in fewer cases children were hospitalized. According to the CDHS (2005), there is a strong tendency to give prescriptions or treatment regardless of symptoms in rural and urban Cambodia.

Figure 17: **Service Received (n=32)**



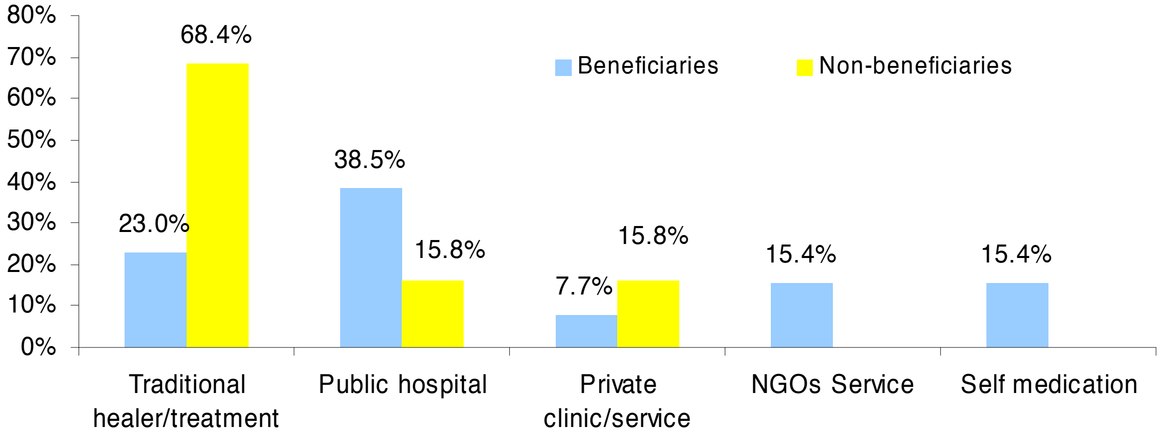
When parents realized that the medicines they had been given at the health facilities were not working, 44.4 percent of respondents began to look for treatment again. Among these, it is interesting to note that half of them (50%) sought a traditional healer or followed traditional treatment, as opposed to the 11 percent who did so in the first round of treatment (see figure 18).

Figure 18: **Place Sought by Parents for Second Treatment (n=32)**



There are also significant differences in the help-seeking behavior between beneficiaries and non-beneficiaries in this second round of treatment (see Figure 19). Thus, while more non-beneficiary families (68%) were inclined to look for a second opinion among traditional healers, beneficiary families chose between public health facilities (38%) and traditional health providers (23%).

<u>Figure 19</u>: Differences in Help-Seeking Behavior between Beneficiaries and Non-Beneficiaries (n=32)



According to Huort's mother:

> *At 5 years of age, my child seemed to have some trouble to walk. At first, I thought that the problem was just a matter of time but then his condition started to get worse. At 6 years, he could not walk anymore and started to show more visible signs of intellectual disability. His younger brother also presented the same case. So I brought Huort to Cambodia Trust to ask for a wheelchair. After I got this chair, I did not seek any more treatment. Later, when Huort was 12, I brought him to the new CBR center of NH. (Case study 2)*

According to the CDHS (2005), most people (72%) in rural areas do not look for second treatment; those who do, seek it within in the private sector (13.1%), the non-medical sector (7.7%) and the public sector (6%) in that order. In this study too, the majority of respondents (56%) did not seek further treatment and among those who did, the public or private sector was replaced by a traditional health provider or the non-medical sector.

This pragmatic switch in behavior regarding the place for second treatment might be explained by two factors. First, parents were profoundly disappointed with the kind of service provided in the public health facilities. Studies show that, within the hierarchical Cambodian system, health services providers mistreat poor people by being rude and looking down on them, making them wait long hours before the consultation and forcing them to buy medicines at their own expenses without giving satisfactory results (Mel, 2004; Hancart Petitet & Desclaux, 2010). Second, parents, according to their local knowledge, believe that some kinds of illnesses are related with the mystical world and therefore can be treated by traditional healers or monks. They are supported in this by relatives, neighbors and other community dwellers who advise them to take their child to the *Kru Khmer*. For families living in remote areas the first choice remains even more so the traditional way (Mel, 2004).

Several respondents decided to stop seeking treatment after the first round on the grounds that this was a waste of time and money. The in-depth interviews provide further insights into their rationalization for this. Their explanation was based on the correlation between the possibility of a cure and the amount of expenditure required for it; in other words, parents were more willing to spend money on their child's treatment if the chances for a cure or better health condition were higher. Since intellectual disability is not an illness but a limited capacity of the cognitive functions, there is no cure as such, although an improvement of capacities can occur with appropriate rehabilitative and educational services over the long term. For parents who realized there was no cure or quick fix for better health, continuing to seek help was, therefore, time and money wasted. For example, one mother took her child with intellectual disabilities to Kantha Bopha Children's Hospital in Phnom Penh as her child needed urgent surgical intervention due to heart problems, but as soon as she learnt of the cost, she decided to go back home. The mother felt that, since her child was already disabled and there was no hope for him to be cured, the expenses for the surgery were not justifiable[17]. In a similar way, Sombol's mother explained:

> *The doctor gave me medicine but my child was still not better. When I came back from Kompong Chnnang hospital, I took him to Ponley hospital, but he got better for only a short time. Then I took him to Kompong Chnnang hospital again. Sombol was better for a few months and then became sick again. The doctors did not tell me clearly about my child's disease. They just asked me about my child's symptoms and then, they gave me some medicines. Because I did not have more money I decided to stop taking my child to the hospital. I just keep buying medicines from the market. (Case study 6)*

Many parents, recognizing the hopelessness of a cure for their children, preferred to risk buying possibly spurious medicines from private drugstores instead of paying doctor's fees. For example, Sok Chea's mother stopped taking her son to the hospital after he was a year old. Instead she chose to treat his severe convulsions with some pain killers and other medicines recommended by the owner of the private pharmacy. (It must be noted that, in Cambodia, many pharmacy owners are not professional pharmacists).

Parents who attributed the causes of their child's intellectual impairment to cultural beliefs were more likely to seek help among traditional healers. For example, in the case of the mother who believed that her child's regular convulsions were the result of a dream in which the soul of a boy killed by a lightning strike asked her if he could become her son led her to believe that her child's condition was not an illness but a sign of the lightning left on the child.

Several parents attributed the child's situation to *Karma,* which is often interpreted within the western context as a fatalistic approach. However, we found in our study that these parents had two different responses to the disability of their child. One response consisted

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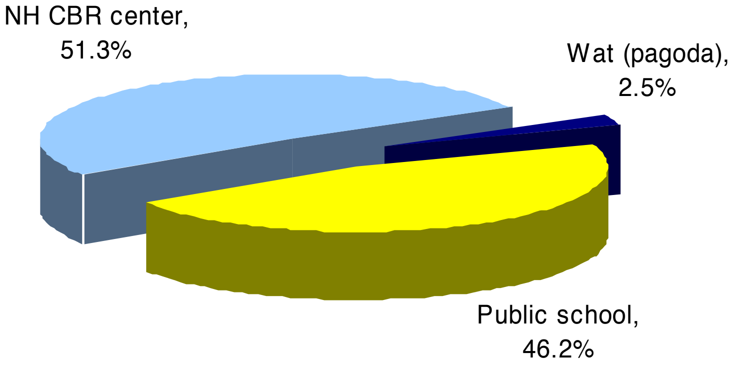
[17] Research (e.g. Filmer, 2005) shows that, in many developing countries, families which have one member with disabilities will be more likely to spend on costly intervention if the member is an income-earning adult, particularly male, than if the member is a child because, in economic terms, the returns on the expenditure will be higher with the adult.

of adopting an attitude of resignation. This attitude drives the family members to have a passive approach towards the child and does not give a chance to the child to improve their living condition or quality of life. Another response consisted of an attitude of active acceptance, that leads the parents to acknowledge the situation as it is (e.g. the disability cannot be cured and will not go away) and then to look forward to what they can do for the well-being of their child[18].

4.5 Access to Education

As long as they were able to keep up with the pace of learning, 54 percent of the children were attending an educational facility, such as a public school, CBR center, or other NGO. However, 46 percent were not, either because the child was very young or their disability too severe. Among the children who had some access to education, 46 percent were going to public schools. This number is expected to grow in the years to come as government schools make an effort to include children with intellectual difficulties in their classrooms. With the exception of one family whose child was receiving an education at the nearby *Wat* (pagoda), the rest of the families mentioned New Humanity's CBR centers as the place where their children were sent on a regular basis (see Figure 20).

Figure 20: Place for Education Service (n=39)



It is significant that there is a huge gap between the perception of beneficiaries and non-beneficiaries regarding quality of services received at public schools and NH CBR centers. Reasons for this gap become clear if we compare several indicators including number of teaching hours, school meals, individualized special education, transportation to educational centers, health care provision, and family support.

While public schools, in general, provide on average 3 hours of instruction per day, the NH CBR centers provides around 8 hours of instruction per day (from 7:30 a.m. to 15:30 p.m.). Additionally, some public schools may offer school feeding funded by the World Food Program in Kompong Chnnang province, although the quality, quantity and regularity are not always assured. However, NH CBR centers ensure a consistent lunch for all its beneficiaries, as one of the most important objectives is to improve their health condition. At present, few public school teachers are trained to teach children with

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[18] Pacot (2007) supports this analysis of resignation and active acceptance as being different responses to difficult events in life, p. 95-96

disabilities, and even fewer have adapted curriculum or teaching materials to respond to their educational needs. On the other hand, NH assesses beneficiaries on an individual basis and develops a plan for educational, physical therapy and other rehabilitation services that is appropriate for and individualized to their needs; this plan becomes the basis for instruction for the year, and is revisited regularly to assess each beneficiary's skill acquisition. In order to ensure the attendance of its beneficiaries, NH centers arrange for a *tuk-tuk* to fetch the children from their homes to the center. Finally, NH centers also offer family support by providing individual and group counseling. Recently, food security activities to improve nutritional status by diversifying diet have been implemented by providing agricultural training to families with children with disabilities.

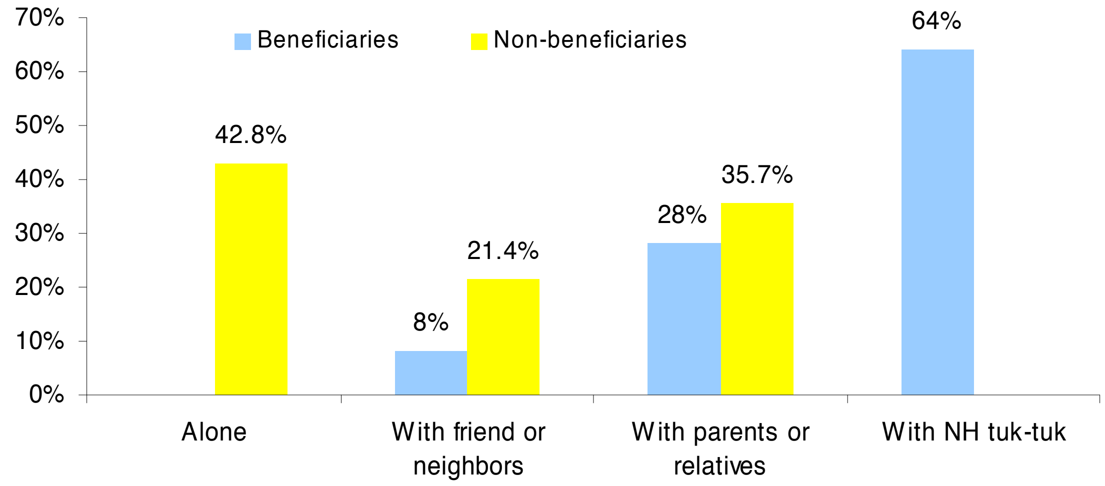
New Humanity also supports and encourages students with intellectual disabilities who can benefit from a public education by arranging for them to go to the public school and be part of the school life in the morning and then participate in the lunch and afternoon activities at the NH centers. Children who may not be able to keep up with the pace of learning in a regular classroom receive instruction in New Humanity's CBR centers which are located within the compound of the school, when possible. These centers dedicated exclusively for children with disabilities offer the range of individualized services mentioned earlier.

Interviews with parents who were not sending their children with disabilities either to school or to New Humanity CBR centers revealed several reasons for this decision. This included the school being deemed too far for the child to walk to, money constraints, and the belief that their child was unlikely to benefit from an education. This was particularly true for some of the rural families in this study living far away from the main villages and public schools, whose geographic location did not encourage them to bring their child with disabilities to school or center.

About 43 percent of non-beneficiary families sent their children to school alone and 57 percent of them arranged for their children to be accompanied to school. On the other hand, only 36 percent of NH beneficiary families made similar arrangement for their children to be accompanied, while 64 percent took advantage of NH offer of free transportation (by *tuk-tuk)*. Long distances between home and educational facilities require time and means of transportation, precious time that families would rather dedicate to income-generating activities at home and in the fields, especially during planting and harvesting seasons.

It is also important to point out that, as can be seen in Figure 21, while more NH beneficiaries were able to send their child to school because they had access to a tuk-tuk for transportation, more non-beneficiary families were likely to seek the assistance of friends or neighbors for their children to access school. While this could be interpreted as an indication of the additional burden a child with a disability places on a family, the fact that neighbors and friends were willing to provide this assistance points to the existence of a sense of solidarity and mutual support as an inherent strength of the Cambodian community. When providing services, NGOs need to tap into and build on such existing strengths so that the development and care of children with disabilities as a communal effort is further enhanced, even as it reduces the burden of care on individual families.

Figure 21: **With Whom the Child Goes to School (n=39)**



The attitudes and behavior of the 46 percent of parents who do not send their child to any education facility must be understood within a context of severe poverty, where the priorities are clearly focused on food procurement (i.e. finding the necessary resources to eat every day). For these families, education for their child with disabilities is a big investment without any security for future returns in terms of income generation. As the research of Carter (2009) also noted, in this context, children with physical disabilities, who are perceived to be more likely to succeed in school and be able to generate an income, are more likely to go to school and benefit from inclusive education than children with intellectual disabilities. In consequence, the latter are more vulnerable. Firstly, their parents consider them to be "crazy" (ឡប់ ([*Lop*]; ឆ្កួត [*Chukuot*]; អត់គ្រប់ទឹក [*Ot Krup Teuk*]), or not intelligent (អត់ពូកែ ([Ot Pukae]), and, as a result, dismiss the idea that their children could benefit from educational services. For example, Sok Chea‘s mother wanted to send him to school but she thought that her son could not be taught since he could not talk or understand anything. All she wished was that Sok Chea “could stand, walk, or eat rice without her help”. Similarly, Vinh’s mother explained:

> *I really wanted to send my son to school but I was worried and doubtful that my child would be able to learn as well as other children, it might be difficult for the teacher too, because teachers in primary school do not know how to deal with my disabled son. (Case study 7)*

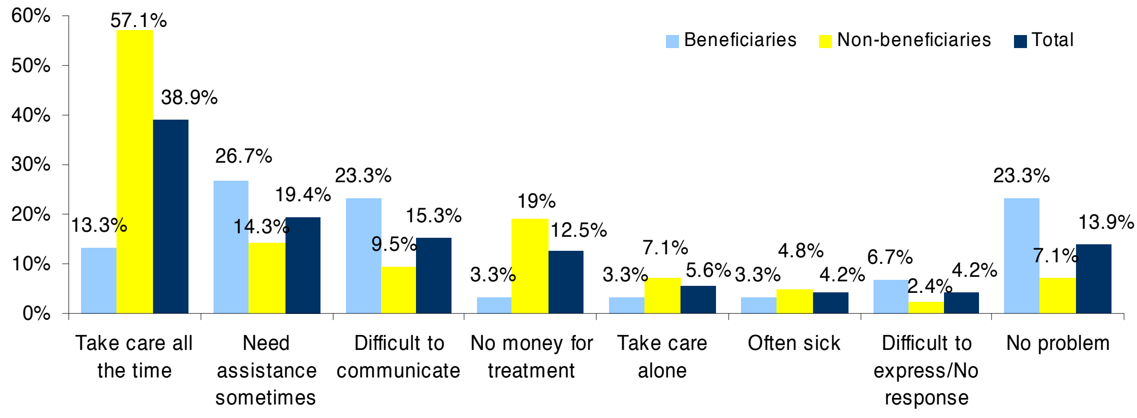
Secondly, children with intellectual disabilities are vulnerable because the majority of public schools do not accept them since the teachers do not have the skills to teach them and are apprehensive about them. Like the parents, the teachers assume that these children are not able to learn at all. This suggests the acute need for training regular education teachers in inclusive education and developing curriculum and training special needs teachers, as well as establishing classrooms for children with intellectual disabilities in both urban and rural public schools. Our study found that most of the teachers interviewed were aware about the government policy on inclusive education, but they were not well-prepared to include children with intellectual disabilities in a regular classroom. Indeed, we observed almost no children with intellectual disabilities actually in school and only a few teachers said they would be willing to receive some children with an intellectual disability, like mild Down syndrome, in their classroom if they received special training.

Although teachers' reluctance to accept children with intellectual disabilities is strongly correlated to the lack of skills to teach them, a third factor makes this group of children more vulnerable: teachers' unwillingness to enter this line of work as a result of the low status accorded to the children and, by association, their families. For instance, even among the NH teachers, several admitted they were attracted to the job only because of the salary attached, and that if they had had the opportunity to choose, their choice would have been different. It must be said, however, that some teachers had undergone a transformation in their attitudes along the way and had begun to value and appreciate their students.

4.6 Challenges of Raising a Child with Intellectual Disabilities

The study found that 86 percent of families identified numerous challenges in raising a child with intellectual disabilities. These challenges included difficulties in communication, recurrent illness, lack of money for medicines and treatment, time consumed in providing care, the difficulty of responsibility for care falling on one person, and need for specialized assistance (see Figure 22). The challenge that most families identified was the responsibility of having to care for the child with intellectual disabilities at all times. Typically, Cambodian children after a certain age, especially in rural areas, are expected to manage their chores and be able to find ways to occupy their time independently or among themselves, without much, if at all, adult supervision – a level of independence that most children with an intellectual disability lacked. Although rural areas afford open spaces for children to play in, there are also hazards, like swift-flowing rivers, deep water channels or artificial lakes, and snakes, that made families reluctant to leave their child alone or out of permanent surveillance. Parents also worried about the dangers present inside the house that precluded unsupervised play for a child with intellectual disabilities.

Figure 22: Daily Challenges for Parents of Children with Intellectual Disabilities (n=72)



This need for constant supervision placed enormous limitations on the parents, particularly the primary care-givers, severely reducing opportunities for gainful employment because they had to stay at home or have someone stay at home all the time to care for their child with disabilities. The situation worsened if the family's economic condition was already precarious, with the possibilities for generating income diminishing further.

Another challenge identified by most parents was the need for assistance, in terms of specialized help provided by people trained to work with intellectual disability. Parents spoke of feeling powerless when confronted by their child's strange behaviors, which they could neither understand nor respond to. In line with this, some parents (15%) mentioned difficulties in communicating with their child, particularly if the child had problems with speech or mobility. They confessed that sometimes they really did not know what their child was asking from them or what they were trying to express in their limited way.

Other challenges related to money issues due to health care costs. The survey found that many parents experienced difficulties in finding the funds to cover health care expenses, especially if the child had a chronic condition. The frequency and intensity of the illness further impacted the family's economic situation adversely. For example, Sok Chea frequently fell sick because of his fragile condition. This meant that the parents had to put out a considerable amount of money to bring him to Phnom Penh, where they could be sure he would receive quality service, to cover the trip's expenses, consultation and medicines. They had tried to put aside some savings for these costs by taking turns to care for Sok Chea while the other parent went out and earned some money, but they still had to borrow money when a medical emergency arose with Sok Chea. In another example, Vinh's family had to sell two rice field plots to pay for Vinh's medical expenses. The resulting precariousness of the living condition of these families was far more common among the respondents than expected, worsening in the case of single-parent families who constituted 31 percent of households surveyed. Through health equity funds, the Ministry of Health has a program for providing free medical services, medicines, transportation, and meals for the patient and a companion, for qualifying families who are deemed to be below the poverty line. Families are issued an identification card that they show at the health center in order to receive these benefits. Since disability can place extraordinary medical burdens on families, it would be helpful if this factor were given additional weight in this determination, so more families with a member with disabilities would have access to medical services without undue cost to them.

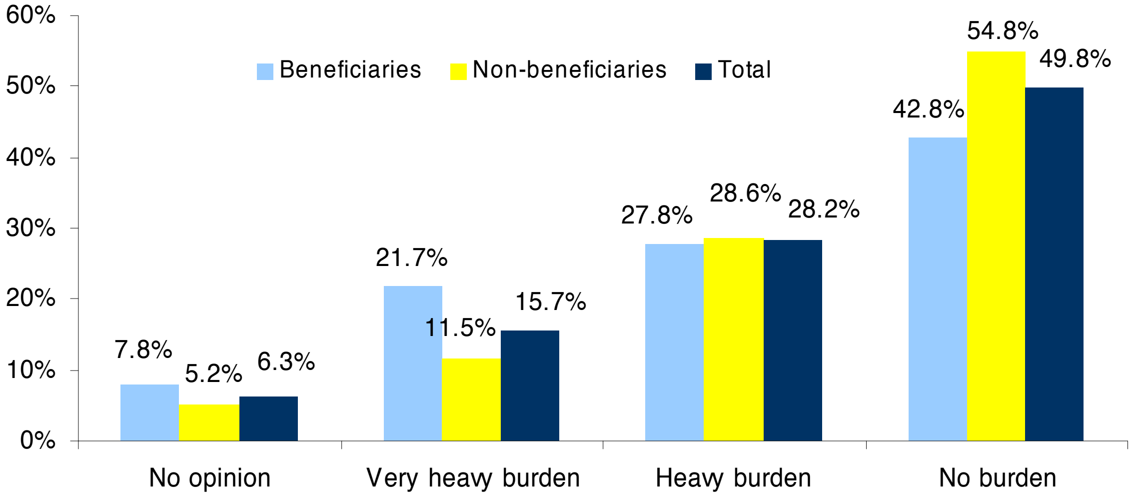
Almost 14 percent of families did not identify any difficulties in raising their children. This may explain why, when asked about their feelings or perceptions about caring for their child, half the parents stated that they did not feel this as a burden. This is discussed in more detail later.

The differences between beneficiaries and non-beneficiaries in their ranking of the significance of these challenges to them must be noted. While the problem of providing round-the-clock care and supervision was a major challenge for most non-beneficiaries (57%), only 13 percent of NH beneficiaries identified it as a major challenge. One explanation is that the NH CBR centers cared for the child with disabilities for eight hours in the day, providing beneficiary parents with a window of time for activities other than caring for their child with disabilities.

Another remarkable difference relates to health care expenditure. Non-beneficiaries (19%) felt the lack of money for buying medicines and continuing longer treatments more acutely than beneficiaries (3%). This difference might be explained by the fact that beneficiary children received health care support as well as psychological follow-up by regular counseling therapy within the CBR centers, thereby considerably decreasing the burden of additional health costs for beneficiaries.

On the other hand, beneficiaries felt more acutely than non-beneficiaries the challenges arising from limited communication (23% as compared to 9%) and access to specialized assistance (27% as compared to 14%). This would indicate that, once families begin to observe the benefits of the services their child receives, they become more aware of the possibilities for development of the child's potential and the need for communication strategies and specialized skills to respond better to their child. Therefore, it is crucial to promote more information to those families about the resources available and the benefit that could bring to the family as a whole.

Figure 23: Perception About Daily Care as Burden (n=72)



Despite these major challenges, the parents stated that, for them, this was "*just part of their daily life*", and not a burden (see Figure 23). About half of them did not perceive themselves to be overwhelmed by these daily responsibilities for their child with intellectual disabilities, which could be as extensive as helping with feeding, dressing, hygiene and toilet use, and even with moving around. This approach may be ascribed to two cultural values. One is the social custom of pre-determined gender roles whereby mothers are expected to play the role of caregivers of all sick people at home. Another explanation is the Buddhist principle in which a given reality is accepted, with no need for changes, as long as this reality does not become an unbearable life situation. According to Paul Magnin (researcher at Centre National de la Recherche Scientifique, France), Buddhist wisdom stresses the fact that human beings must learn to look at things in order to be detached from painful existence, a process towards an "awakening" or *Nirvana*.

> [Buddhist wisdom] *is a clear and precise vision of the Four Holy Truths, by an intuition of the four characters of all things: their transitory nature, the suffering that results, their lack of ego, and the possibility for any person to ever reach the nirvana. This wisdom which sees things as they truly are and that frees the mind of all impurities, must be provided with several qualities: denial,*

> *detachment not selfish spirit of love and non-violence (ahimsa) extended to all beings*[19]*. (Magnin, 1997)*

However, 28 percent admitted that this permanent commitment sometimes became difficult to deal with, while 16 percent felt that the need for constant care was tiring and difficult to cope with in the long term, and recognized that their families were making big sacrifices to carry this heavy responsibility. During our observations, we noticed that several children needed help for basic self-care tasks. Some children had additional mobility limitations that necessitated parents or close relatives having to help to change their position or move them from one place to another. While all young children require high levels of care, the intensity of need lessens gradually as they grow up and can undertake these tasks by themselves. Children with intellectual disabilities, however, may never fully acquire all these capabilities and could remain dependent on a parent for many years, even for life. As a result, many respondents showed symptoms of deep physical and psychological exhaustion. For example, some mothers confessed that they felt exhausted all the time.

> *My child cannot do anything without my help including bathing and defecating. Sometimes Kunthy is so mean and aggressive, throws everything away. I cannot take her anywhere or participate in any ceremony. (Case study 8)*
>
> *It is so difficult to look after her, because she cannot do anything without some help as eating, taking shower, defecating, sitting, standing, and etc. Once I was very busy in the rice field so I decided to ask other siblings who stayed in the same village to look after Chiva instead of me. However I could not do this often because they were also busy and bored to look after my child. I was very busy looking after Chiva and I did not have time to do other work and also attend in other ceremonies in my community because I could not leave her alone or ask somebody to look after her. (Case study 1)*
>
> *I do not have time to work and sleep, because at night I wake up several times to attend to her. When my child is sick, it is worse. (Case study 5)*

4.7 Support Provided to Families

Among all the families interviewed, only 37.5% respondents confirmed receiving some kind of support, although many more were receiving services (see Figure 24). This contradiction is not surprising: some families chose not to disclose this information in the hope that they might receive more support, while other families did so in the fear that the support they currently received might stop. Additionally, beneficiaries may have had different understandings about the meaning of support; for instance, their expectation in terms of support may be related to cash or in-kind materials, and, as a result, services provided to their child were not considered as support. Within the group of families willing to admit being beneficiaries of some service, 89 percent stated that they received support from New Humanity NGO, 15 percent referred to support received from other NGOs like Cambodia Trust, 11 percent declared they received support from public health facilities, and 7 percent mentioned support they received from neighbors and/or community members. Some families received support from multiple sources.

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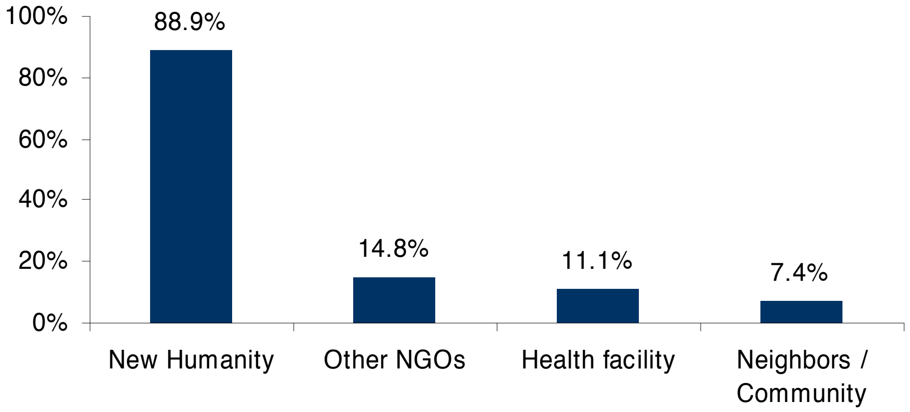
[19] Paul Magnin (1997), *Buddhism and the mystical experience.*

Figure 24: Type of Support Received (n=27)



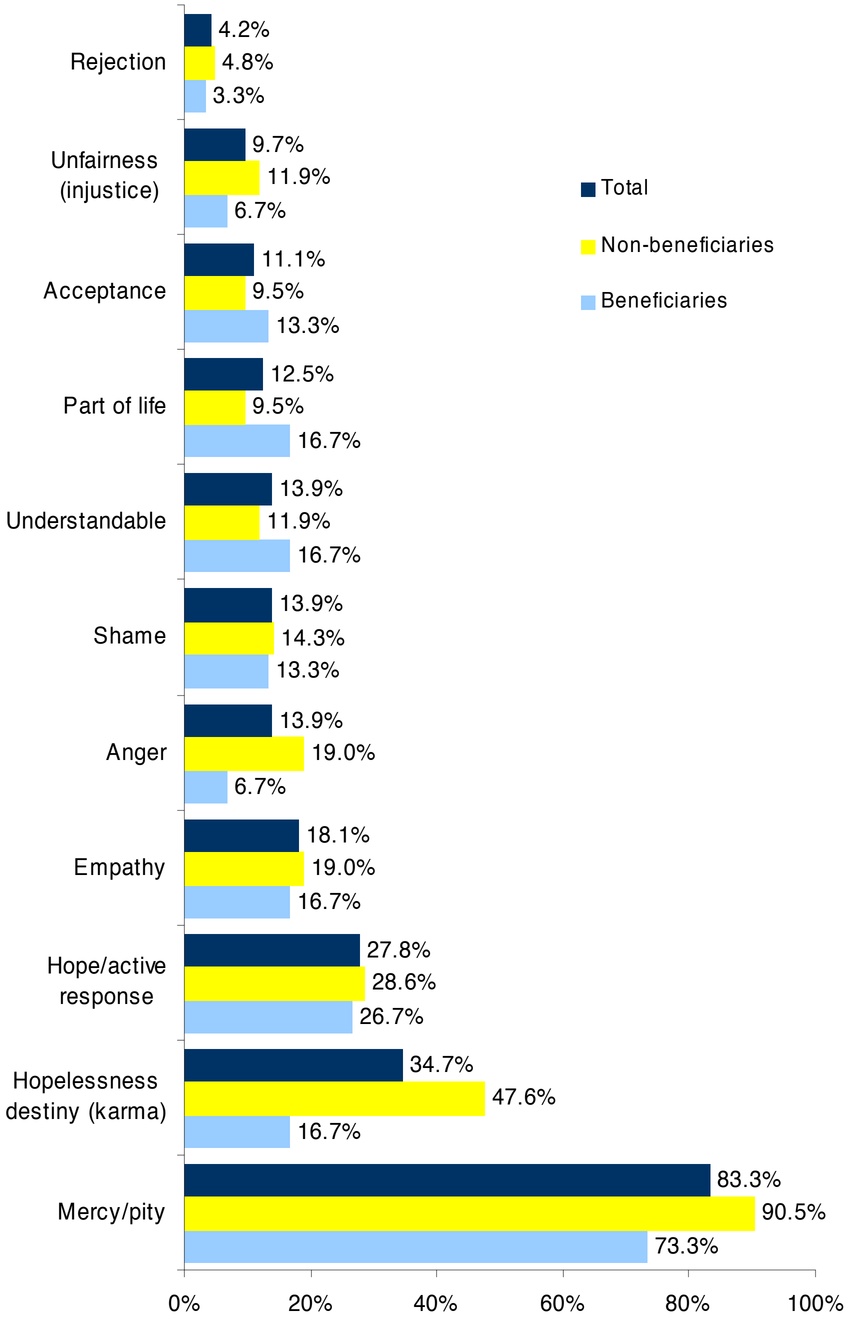
These data suggest that NGOs are the main source of support for families with children with intellectual disabilities. Since there are very few NGOs that provide services for children with intellectual disabilities in the entire country, and most have limited capacity for admission, this means that the majority of parents who are seeking such support may have to face the harsh reality that no services are available for their child. The problem is further exacerbated for families in rural areas as most of the agencies are located in urban areas. It is hoped that with the government's adoption and implementation of the *Law on the Protection and the Promotion of the Rights of People with Disabilities*, 2009, children with intellectual disabilities will have greater access to services, in particular, free consultation for health care. As Figure 24 shows, only 11 percent of families went to public hospitals to avail of this service. The reasons for this low percentage might be due either to families' ignorance of this new policy mandating free consultation or the rural health centers' inability to provide reliable services. Therefore, it is crucial to disseminate information about this Law and encourage families to use these health care facilities. However, it is also important that rural health care facilities be able to offer qualified service or at least implement a system of referral for specific cases of intellectual disability, so that families can look for support in appropriate places.

4.8 Feelings of Parents Towards Their Child's Condition

This study found that parents had varied feelings towards their child's condition (see Figure 25). These feelings may be placed in two categories: positive feelings and negative feelings. Among positive feelings are included empathy, pity, hope, acceptance, and understanding, while among feelings of despair are included anger, shame, hopelessness, despair, rejection, unfairness, and injustice.

It is significant that, as Carter's study (2009) also found, the most common feeling expressed by the families interviewed was pity or compassion (82%). Despite the challenges they faced in their lives every day, parents showed a compassionate disposition to help their children. This attitude of willingness to help is critical for an active commitment towards meaningful changes for their child's condition. Other positive feelings some parents (28%) expressed were hope[20], empathy, acceptance, and understanding. The implications for professionals are clear: these positive feelings of hope and acceptance should be encouraged and transformed through collaboration into attainable expectations by building a common strategy between parents and health care providers.

Figure 25: Parents' Feeling Towards Their Child (n=72)



Although most parents had positive feelings towards their child, some expressed negative feelings. Thus, 35 percent of parents admitted to a feeling of hopelessness, and others

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[20] Research (Turnbull et al., 2010) on families has shown that this feeling of hope expressed by many parents, of having expectations for their child, is often interpreted as "denial" by professionals, in that parents are denying the child's limitations by expecting a brighter future than justifiable. Researchers who are themselves parents of children with disabilities have clarified that parents are well aware of their child's limitations and that having dreams and setting goals for their child helps to focus on what the child can do and to work towards achieving their potential instead of focusing on what the child cannot do.

mentioned feelings of injustice, anger, shame, despair and rejection. Some of these feelings might be linked with the cultural expectation in which Cambodian parents, traditionally, expect their children to care for them in their old age. The realization that these expectations could not be met due to the child's impairment can engender negative feelings in parents towards their child.

In the case of one child with severe intellectual and physical disabilities who had died, her mother saw the departure as ស្រស់ថ្លា ([*Sroj Tla*]), an expression used to describe the feeling of relief of a person after sickness, sadness, or period of worry:

> *"Now I feel relief, better, and easier than before. My husband and I can save more money because both of us have enough time to earn money and we also do not spend more for Chiva's health expenses. For me, I have free time to make money from selling the firewood or go to rice field in helping my husband. Besides doing rice field, my husband can find a lot of firewood for selling outside the village. Moreover, he can stay outside house/village a few nights for selling the firewood without being concerned about the family. On the other hand, now I can do more things instead of him at home and rice field." (Case study 1)*

On the other hand, where the disability of the child was severe, the parents appeared to have a strong sense of acceptance that the disability was a normal or regular (ធម្មតា [*Thomada*]) part of their life.

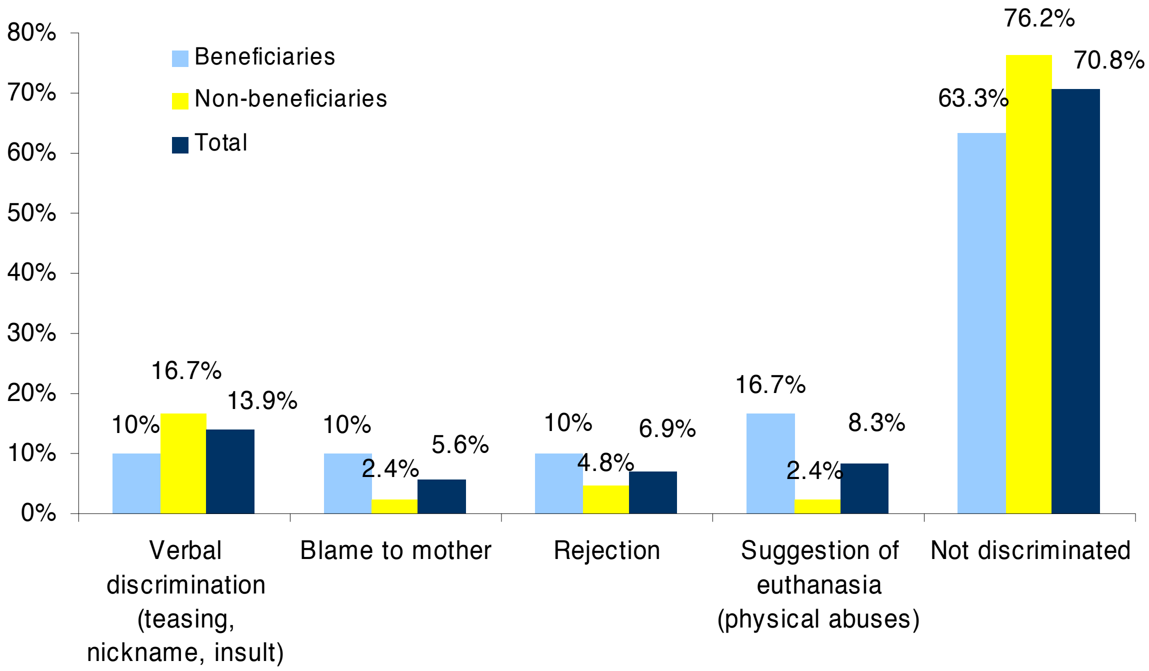
This sense of resignation and the belief in *Karma* are strongly related to cultural parameters like the Buddhist principles mentioned earlier. However, it is incorrect to assume that these beliefs and behavior, intrinsic to most Cambodians, are unchangeable. Comparison between the two groups of beneficiaries and non-beneficiaries found that 60 percent of non-beneficiary families expressed feelings of hopelessness and the disability as a "normal part of life" against only 17 percent of beneficiaries. It would appear, then, parents who do receive services have a better understanding of their child's condition and have observed the benefits of these services for their child, and begin to feel more optimistic and hopeful about their child's future, and that parents who do not receive services are much more likely to feel hopeless and resigned. This direct relationship between being a beneficiary and having hope for one's child underscores strongly the need to provide services that target and involve not only the child with the disabilities but also family members, such as counseling and information sessions. The more parents are informed and instructed about their child's intellectual disability, the more parents feel involved and are eager to do something to help their child.

4.9 Experience of Discrimination

In this study we define discrimination as *behavior or treatment that denies to the members of a* particular *group, resources or rewards that can be obtained by others* (Giddens: 2003)

Interestingly, only 29 percent of parents thought that their child with intellectual disabilities had experienced some kind of discrimination (see Figure 26). Indeed, neighbors, school teachers, and local authorities alike thought that children with intellectual disabilities were not discriminated against. Analyzing discrimination within a geographic and socio-cultural context offers some explanations.

Figure 26: Type of Discrimination (n=72)



The context in this study is rural Cambodia, where social links are defined by a strong sense of kinship and community. In order to better understand this highly-developed sense of community we could refer to the theory of *Gemeinschaft* (community), developed by F. Tonnies, which assumes that the will of all humans is united and that this is their natural condition. This natural condition responds to three basic laws:

> *(1) blood relatives and married couples, neighbors and friends feel affection for each other and have common beliefs and customs; (2) this affection and similarity in beliefs and values creates "understanding" (3) by virtue of this love and understanding, the members of the group tend to stay together and the result is the community type of relationship. (Tonnies, cited in Perdue, 1986)*

As a result of this highly-developed sense of community in rural Cambodia, any person who is perceived to share "the same beliefs and values" is included within the community. By the same token, in the hierarchical Cambodian culture where status and conformity are highly valued, a person who does not share these values is excluded or not valued. However, that this exclusion is a form of discrimination is a more recent sensibility – indeed, the original Khmer word រើសអើង [ruh ahng] for the action of "not valuing a person who does not share (the same socio-economic status/ race/ religion/ other beliefs)" has now come to be used to mean discrimination – that may not prevail among those less tainted by western perceptions. In a culture where the concept of value-inequality is so deeply imbedded, a child who would not have the intellectual capacity to share the same beliefs is likely to have less value. While the outcome may be discriminatory, the intention is less so, a distinction that is important to and must be considered carefully in disability awareness-raising and attitude-changing campaigns or strategies.

The case of special needs teachers from NH CBR centers who come from the same villages of the selected respondents is interesting. They were actually able to perceive discriminatory behaviors more easily than other villagers, but their similar cultural background made them also more tolerant of discriminatory behaviors that in other western contexts might be considered as clear acts of discrimination. Therefore we should perhaps shift our focus to understanding the different ways that children with intellectual disabilities are stigmatized, taking into consideration local cultural parameters instead of imposing revolutionary changes of attitudes by integrating so-called universal values subscribed in the human rights declaration.

This study indicates that a better understanding and deeper analysis of the socio-cultural context in Cambodia can provide us with alternative explanations for this discrepancy between western and Cambodian world views. As a result, although some siblings, relatives, or close people would call children with disabilities by negative nicknames, parents do not consider this verbal action as discriminatory but rather as ordinary jokes that might be considered as a way to recognize the existence or presence of the children with disabilities, giving them a place in society.

This pattern was also observed among parents who used nicknames or offensive appellatives to call or describe their children's disability perhaps as a way to give them an identity within the family and community. For example, in our research, we found that a young girl with Down syndrome was commonly called ជ្រូក ([chruk] – pig). Ingenuously, we thought that this was her nickname due to her physical appearance, but later on we learned that this was her real name affectionately given to her by her own parents.

Nicknames or name-calling is just one kind of discrimination. According to our observations, there are other ways where discrimination occurs in the community, such as social exclusion, rejection, negative criticism, insults, blaming the mothers, and even suggestions for euthanasia. For example, in our research, we came across several instances where NH staff, neighbors, and families themselves testified that, during a visit to the family's home, children with intellectual disabilities were sometimes kept inside a locked room in order to prevent them from meeting the visitors. During our short fieldwork we did not observe any signs of discrimination. It is possible that parents and other key informants were careful about doing or saying something negative against their child with disabilities in front of us.

The families accepted that their child with intellectual disabilities had less value in society: locking the child away to prevent them from interacting with visitors was as much from shame and wanting to protect the child as from a sense of courtesy and respect they were extending to the high status visitors. Nevertheless, some parents recalled occasions when friends or neighbors were reluctant to invite them with their child with disabilities to ceremonies held by the community for fear that being near the child with disabilities could be a bad omen and affect their own *Karma* or the traditional ritual. The parents saw these experiences as discriminatory because they rejected and excluded their children from the social life of the community.

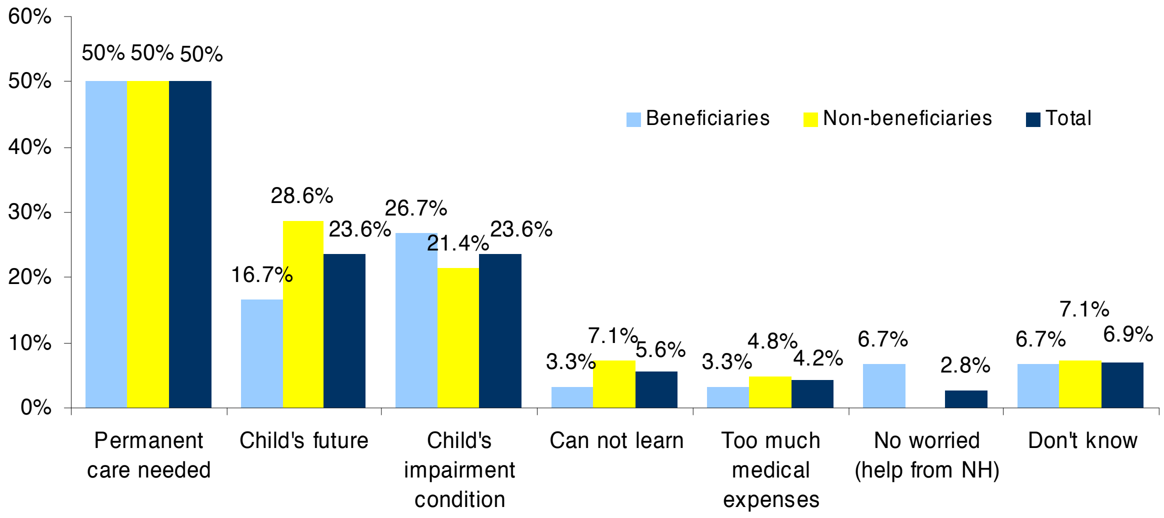
Consequently, not only children with intellectual disabilities are subject to discrimination, but also their families, especially mothers who are seen as directly responsible for, even the cause of, their children's situation. Some neighbors believed that the disability was probably caused by the mother's use of some form of birth control method[21] or because she had behaved against the traditional norms expected of a woman. According to some special needs teachers of NH CBR centers, there were some cases where close friends or neighbors suggested euthanasia as a solution to the mothers. Such discriminatory attitudes served only to impose blame on the mothers and drove them to states of depression and psychological fatigue, in addition to the difficulty of raising a child with intellectual disabilities.

Parents perceived certain acts as discriminatory as long as they were the victims, but did not think similarly about exclusionary behavior when they were the perpetrators. In consequence, service providers were more likely to identify these acts as discriminatory, not only because they were objective outsiders looking in but also they had received training to recognize these behaviors as such. It was also a sensitive topic, especially when neighbors or relatives were around during the interviews — a common practice in rural area — as people approached us as soon as we arrived at some houses. Therefore, it is very likely that parents were less informed in such circumstances. Besides, as we have already explained above, the concept of discrimination depends mostly on the interpretation and experience of each individual.

4.10 Parents' Concern and Expectations

Parents also expressed their concerns and expectations about their child's future (see Figure 27). They were clearly worried, in the event that they predeceased their child, about who would look after their child and be available at all times to answer their needs.

Figure 27: Parents' Concern About Their Child (n=32)



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[21] According to the Research on Reproductive Health in Cambodia by Hancart Petitet (2010), people believe that contraceptive methods trigger body-functioning disorders, because they create an imbalance between the elements (air, fire, earth, and water). This imbalance can produce changes in body temperature or "body drying out". Therefore a dry body is unable to have fluid blood discharge. It is believed that the more blood is going out the better is the process of purification. Then if contraceptives provoke body disorders, these undesirable side effects might be transmitted to the child.

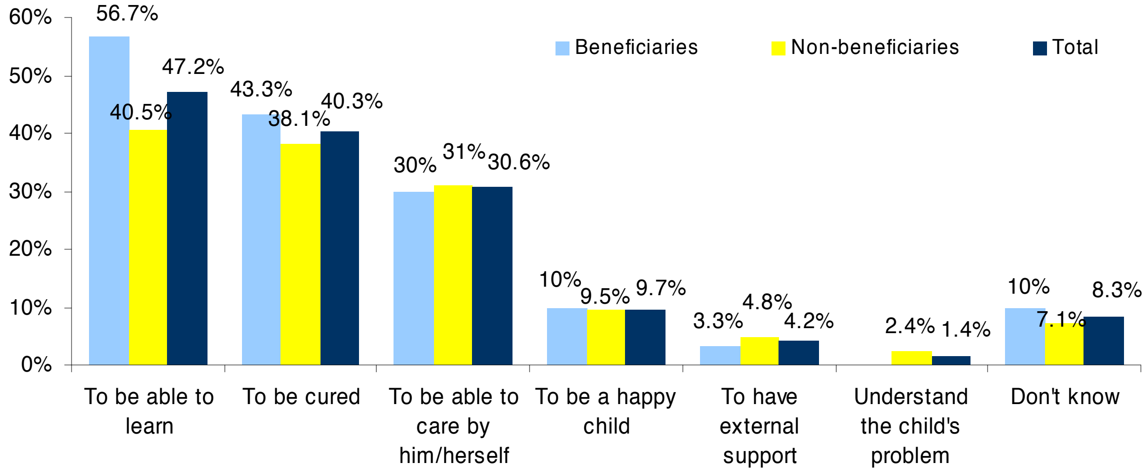
This concern was especially acute among families whose child's disability was particularly severe, as parents worried about the reduced capacity of their children to support themselves in the future. The major concern of parents was care (50%); they were aware that their child with intellectual disabilities required constant and permanent care, as this was a daily challenge for them. Research indicates that the issue of permanent care and parents' strong concern about their child's future is directly linked with the severity of the impairment (e.g. Turnbull, et al., 2010).

The likelihood of parents being more concerned about their child's future if the child were more severely impaired should be taken into account by service providers. One strategy that service providers might use to alleviate some of this concern for parents is to engage in a discussion on this topic early on by encouraging parents to share their fears for their child's future and then considering some practical solutions among the options that may be available. The more parents are involved, informed, and reassured, the better will be the results in favor of children with intellectual disabilities.

It is significant that, with regard to the concern about child's future, the beneficiary families (17%) seem to be less worried than non-beneficiaries (29%). The reason may lie in the fact that beneficiary families had more hope about their child's possibilities for rehabilitation, had a better understanding about the causes and had begun to observe their child's progress, so that there was less pressure to "find a cure". Indeed, parents' awareness is the first step towards acceptance. Information about disability and progress observed by the parents can have an important impact on their perceptions and concerns for their child's future. By contrast, non-beneficiary families did not have access to the same information and results from public health care facilities.

Parents also expressed their wishes and dreams for their child (see Figure 28). The most common expectations were linked to access to education, cure, and self-care. The first one is related to the concern of the child's future as parents made the correlation between a child's ability to learn and better future, similar to parents of non-disabled children. The second wish is more in line with the impairment; parents expected that one day their child would be completely relieved of this disability. This expectation should be discussed by service providers to make clear that intellectual disability cannot be "cured", and explain the potential for improvement by providing an education for their child now.

Figure 28: Parents' Wishes/Expectation (n=72)

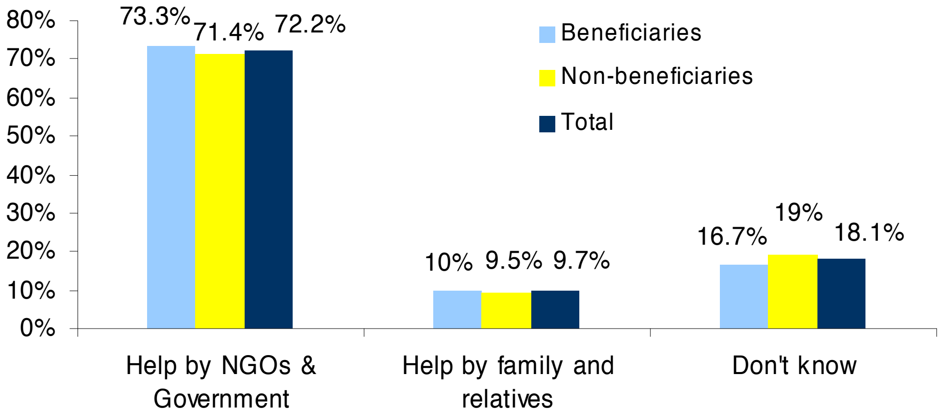


The third most important expectation was an improvement in the child's ability to care for themselves. In the context of this study, self-care refers to the ability to take care of one's personal hygiene (such as toileting, bathing, dressing) independently. These wishes closely connect with the most common daily challenges identified by parents.

Other wishes the parents expressed were the desire to understand more about the disability of their child, including causes of the disability, potential for improvement, and the possibility of finding support outside their community. Some parents expressed their wish for a better life and happiness for their child.

When asked how they expected to achieve these wishes (see Figure 29), the majority of parents (72.2%) reported that they put all their trust in the support and work of NGOs (CBR activities) and government (public health care and educational facilities): "*with the help of Angkar (NGOs) maybe our children can get better".* In particular, parents of children with mild intellectual disabilities were more likely to consider sending their child to public schools as an option. A much smaller group of parents (9.7%) stated that their expectations could be achieved by the care and teaching coming from them and other relatives. Although this group is small, it is significant in terms of parents' commitment and involvement towards accomplishing their goals for their children. This attitude is indeed a positive step of taking co-responsibility for their child's development.

Figure 29: How to Achieve Their Wishes/Expectation (n=72)



4.11 Challenges for New Humanity CBR Staff

As stated before, there are few qualified people in Cambodia who are trained to provide rehabilitation and special education services to children with intellectual disabilities. In the rural areas, the situation is even worse, as the few people who have been trained tend to remain within the main cities, such as Phnom Penh. The New Humanity CBR centers are managed exclusively by Cambodian nationals, with all staff having received training according to their positions. These trainings include basic physiotherapy, occupational therapy, speech therapy, and art therapy, to name a few, provided by international consultants. Yet, the staff faces many challenges.

According to interviews conducted among 13 NH special needs teachers, the biggest challenge was teaching hygiene and health care to the beneficiaries and their parents as well. Most of the staff agreed that, although they had repeatedly provided the same information about personal and family hygiene, the hygienic condition of children coming to the centers remained rather poor. Despite the efforts of the NH staff to improve the condition of their beneficiaries, including providing baths to students, teachers felt that parents were not making an effort to maintain this level of hygiene for the child and the rest of the family, and there was little to no continuity at home with what was done in the centers. However, the study suggests that, if a real change is expected, the service providers must work more closely with parents, not only by increasing their awareness of the need for better health and hygiene at home, but also by identifying the barriers parents experience in maintaining these standards and mutually deciding on practical solutions towards achieving these goals. For example, we found during our field observation that most of the children with intellectual disabilities lived in very unhygienic and unsanitary conditions. All the children live on the ground, exposed all the time to insects and other kind of worms. Since they have no access to safe water they are also exposed to all kind of gastro-intestinal problems. Because some children with disabilities are unable to express their needs, they remain dirty for quite a while before the parents proceed to clean them. Difficulty in terms of hygiene increases accordingly with age, thus the older the person with disabilities, the less attention they receive. So a young adult with disabilities is rarely taken outside of the house for defecation and could be left in the same place for hours. Mothers, who are the persons in charge most of the time, are not strong enough to move their young adult son or daughter with disabilities from one place to another. With technical and some financial support from service providers and the NGO, parents could be encouraged to provide a small pallet for the child to spend their day on, to get access to safe water which would benefit the whole family, and engage a neighbor who, for a small incentive if necessary, would be willing to help the mother with toileting at regular intervals.

Teachers also expressed concern about the practice of self-medication by parents, although this is a widespread practice across the country, and even among the special needs teachers themselves. They noted that some parents bought medicines without prescriptions or regard for their effectiveness or appropriateness to the treatment, a behavior that could put their children at risk. Teachers spoke of some desperate parents giving medicine to their children every day as long as the drug provided partial relief. Although this conduct is understandable, since parents are looking for desperate solutions, efforts by the staff to make parents aware about the side effects that a recurrent dose administration of some drugs could cause, such as other permanent effects or collateral damages, had not had much effect. A strategy to reduce this problem could be to have a resource person (such as a doctor or at least a nurse) available at these CBR centers who could be a source of information or a referral point on medication and dosages for special needs teachers and parents as well.

Like the parents, the special needs teachers also found the task of caring for the children with intellectual disabilities a challenging responsibility, especially because they spent an important part of the day with them (eight hours for five days in the week). They noted that the needs of children with intellectual disabilities were more than those of children who had only physical disabilities, and that it required considerable creativity and patience to teach a pupil even basic instructions. While many expressed sympathy for their students, some acknowledged that they often felt disappointed or frustrated because verbal communication between student and teacher was so limited:

> *"I need a lot of patience for teaching children with intellectual disabilities; it is hard to make them pay attention. Very often I feel frustrated, looking at the kids and their limited improvements after therapy and teaching" (Chanthy, special needs teacher in Popel CBR center).*

The special needs teachers also faced the challenge of persuading parents to send their children to the CBR centers and participating in CBR activities. Believing that parent involvement is crucial to the progress of a child with intellectual disabilities, and that parents need to learn how to care for their own child to ensure constant and consistent care, they were frustrated that many parents did not see the value of the services the CBR center provided, and did not bring their child to the center regularly, or that several parents, after dropping off their child at the center, saw this time as a much-need respite for themselves and were unwilling to participate in the parent training activities.

Teachers expressed concern for their students' health as well. Many of them, they said, were underweight because the parents believed they had spent enough money on them already and did not provide enough food and clothing. The children's diets were inadequate both in terms of quantity and quality as many parents fed them only plain rice with water, arguing that their children could not eat other kind of foods. At the centers, one of the main objectives is to ensure that beneficiaries maintain a healthy weight to avoid health problems later on, so children eat diverse food composed of rice, vegetables, fish or meats.

Finally, the teachers' own level of educational attainment was an important factor affecting the challenges they faced. All the special needs teachers had completed between grade 9 and 12 of schooling and were more comfortable learning by imitation ("seeing and doing"), which involves more applied practice rather than by reading theory or methods through textbooks. However, the limited numbers of trained special needs teachers in Cambodia and the expense of bringing in international consultants for training meant that these opportunities for hands-on learning were few and far between, not to mention too short and often lacking in continuity. Although the teachers could have supplemented their knowledge by reading the extensive materials on disability developed by NGOs and other international institutions that were more easily available, the fact that most of these materials are in English severely limited their access. Therefore, building the capacity of staff towards providing quality service is a major challenge not only for NH but for other organizations working in this sector as well.

CHAPTER 5
Conclusions and Recommendations

5.1 Conclusions

5.1.1 Cultural perceptions of intellectual disability

In conclusion, the study found that Khmer words to describe disability in general in Cambodia are not inherently negative and often have a spiritual origin, such as the term ពិការ [*Pikar*] which means “transformation”. Words to describe intellectual impairment tend to have more negative connotations, such as ឆ្កួតជ្រូក ([*Chhkuot Chruk*] - mad pig) and ស្កន្ធម្ដាយដើម ([*Skon Mday Deum*] - “evil spirit of one’s previous mother”) to describe epilepsy, nerve paralysis, and meningitis. Because of the spiritually-based etymology, parents are more likely to seek traditional healers or *Kru Khmer* for treatment that will release the evil spirit. Efforts to move to more neutral terms, like ពិការខួរក្បាល ([*Pikaa Khuo Kbal*] - Brain with disability), មានបញ្ហាខាងសតិបញ្ញា ([*Mien Pañeja Khang Sati Paññaa*] - "have problem related to mind's intellect"), កំសោយបញ្ញា ([*Komsaoy Paññaa*] Weak intellect) or បញ្ញាអន់ ([*Paññaa On*] - poor intellect), have tended to remain within professional spheres and not reached rural areas yet.

The study also analyzed traditional and contemporary perceptions of disability and found that, in antiquity, people who “overcame” their disability through a benevolent deed or an encounter with the Buddha were accorded the status of non-disabled people. This was primarily reserved for people with physical disabilities. In contemporary times, attitudes towards people with physical disabilities, perhaps because of high prevalence rates as a result of conflict and UXO accidents, are more accepting and inclusive. However, attitudes towards people with intellectual disabilities remain segregationist, rendering people most vulnerable to discrimination. There is a long way to go before people with intellectual disabilities will be considered full citizens, more so in rural Cambodia.

The traditional folktales and life stories of people with disabilities in antiquity clearly demonstrate the existence of a hierarchical structure in the Cambodian worldview in which the value of an individual and the level of social acceptance was ascribed according to the type of disability. In this hierarchy, people with motor impairment (ជនពិការដៃជើង [*Chun Pikar Dai Chung*]) and deaf people had a higher social status than people with intellectual and mental disabilities (មនុស្សឡប់សតិ [*Monus Lop Sati*]) because they were perceived to have the capacity to “overcome” their disability. On the other hand, individuals with intellectual disabilities were and continue to be denied full acceptance in society and recognized as full citizens because, for example, they are “not even able to get married”, an important indicator of a person’s capacity to fulfill their responsibilities within Cambodian society. However, it must be pointed out that, although people with physical disabilities may have more chances for social promotion in contemporary Cambodia, they are still discriminated against, and continue to have less access to employment.

5.1.2 Challenges faced by families

The majority of the respondents to our survey lived in poor conditions with little food to eat and only basic shelter to protect them. The families had worse living conditions than their neighbors due to the frequent medical expenses relating to their child’s condition. The children with intellectual disabilities were more exposed and vulnerable to sickness, and even common infections could cause their death. Beneficiaries appeared to have more and steadier sources of income. We may conclude that families receiving services were able to generate more income because they had more work mobility, in that they did not have to provide constant care for their child with disabilities, during which time they were able to work for money.

Most of the mothers interviewed received antenatal care at a health facility, while a few went to traditional healers. However, when delivering their babies, more mothers were likely to seek traditional birth attendants or midwives than go to a public hospital or private clinic. More mothers sought postnatal than had sought antenatal care, once again preferring to see traditional healers. We may conclude that while mothers are more likely to seek postnatal than antenatal care, they are also more likely to choose traditional forms of care and healing than modern services in hospitals and clinic, especially during delivery and for postnatal care.

An equal number of parents believed that the causes of the disability were medically-based as culturally-based. Most parents explain intellectual disability through a combination of traditional beliefs and Buddhist principles such as *Karma* with conventional definitions that have been given to them by health providers. Within the domain of culturally-based beliefs, many parents attribute spiritual causes to intellectual disability, such as actions in previous lives or attacks by bad spirits. Research on other cultures, such as the Hmong, indicates that this interpretation is not exclusive to Cambodian culture. We may conclude that parents attribute intellectual disability to both medical and cultural causes, the latter based on the Buddhist beliefs of *Karma* and re-incarnation that suggest spiritual or supernatural intervention.

Many parents noticed differences from the norm in behaviors and physical growth within the first year, although they did not yet connect the symptoms with a disability or lifelong medical condition, and sought treatment for their child among traditional healers in or outside their community. Regarding early detection by health providers, less than 50 percent of parents who brought their child to either public or private health facility said the health professionals were able to recognize the child’s disability and give advice. The rest just received a common prescription for some medicines. A few parents who noticed that their child's condition had not improved continued their search for other results through different people, methods, and places. While parents were more likely to seek modern forms of treatment the first time they went to a healer, they became more likely to seek traditional treatment the second time they sought help. Parents who attributed the cause of their child's intellectual impairment to cultural beliefs were more likely to seek help among traditional healers. We can conclude that the more information stakeholders receive, the more likely they are to know about the prevention, identification and treatment of disability.

More than half the children were receiving educational services, of whom almost half were at public schools. Some families with a child with mild Down syndrome had tried to send their children to the public school, but with limited success. Most children with more severe intellectual limitations were unable to attend public schools because teachers were apprehensive about them and their own lack of skills to teach these children. Some families had the opportunity to send their children to New Humanity's CBR centers, where they receive special education and rehabilitation services. It is likely that as more teachers receive specialized training and more parents can access auxiliary services in addition to an education, more children with intellectual disabilities will be sent to school.

The biggest challenge for parents in raising a child with intellectual disabilities was providing constant supervision and care of the child, as this meant that the family had to forfeit the income this family member could have earned even as it increased the workload of household chores, like gardening or taking care of the cattle, on other members. Another challenge was the need for assistance (specialized or technical help) for their child, especially relating to difficulties with communicating with their child. Other challenges related to money issues, due to health care costs. Several families stated that the need for constant care and a permanent commitment was tiring and required enormous sacrifices from the family members and many families showed symptoms of deep physical and psychological exhaustion. While beneficiaries experienced this to a slightly lesser extent than non-beneficiaries as the former had access to educational and health services, which reduced the burden of care and health care costs, as they began to observe the benefits of these services, they became more specific in their expectations in terms of the need for more specialized skills to respond to their child. Interestingly, however, about half the parents stated that looking after their child was "just part of their daily life," and did not perceive the child as a burden. This might be explained by pre-determined gender roles whereby mothers are expected to be caregivers, and the Buddhist principle of accepting a given reality.

Although beneficiaries constituted almost half the sample, only 37% admitted to receiving some support, perhaps in the hope that they might receive more support or in the fear that the support they currently received might stop. Most of the families stated that they received support from NGOs, such as NH and Cambodia Trust, while a few received support from public health facilities or neighbors and community. We can conclude that while NGOs are the main source of support for families with children with intellectual disabilities, the limited number of NGO services, especially in rural areas, means that the majority of families do not have access to services for their child.

Parents had positive feelings and negative feelings about their child's condition. Most of the parents who felt positively towards their child said they felt compassion or pity. Others expressed hope. More beneficiaries expressed pity and hope than non-beneficiaries. Some of the parents who had negative feelings said they felt a sense of hopelessness.

Where the disability was severe, parents said they felt despair, which was alleviated by resignation and the belief that this was the child's *Karma*. Parents who received services had a better understanding of their child's condition and, having observed the benefits of these services for their child, began to feel more optimistic and hopeful about their child's future. On the other hand, parents who did not receive services were much more likely to feel hopeless and resigned.

The parents' understanding of exclusion and discrimination was different from that of New Humanity staff. Parents did not perceive their behavior towards their child, which might include pejorative nicknames or locking the child during a visit from the professionals, as discriminatory but as indications of affectionate humor and respect for the visitors. They did see the behavior of other community members, such as people not visiting them because they had a child with intellectual disabilities, suggestions to euthanize the child, or not being allowed to bring their child to the pagoda or village festivals, as discriminatory, even as they recognized that their child had less value in society. NH professionals who had received awareness training about discriminatory behavior saw the behavior of both parents and community members as discriminatory and attributed community members' attitudes to the belief that the mother was to blame. These contradictory points of view might be the result of different expectations and interpretations of attitude and behavior of people in the community towards children with disabilities: the concept of discrimination depends mostly on how the individual interprets their experience.

Finally, the majority of parents worried about the future of their child. A major concern that almost all parents identified was the worry about what would happen if they predeceased their child. Parents also had wishes and expectations for their child. Expectations were linked to education, finding a cure, and the hope that the child would become independent in self-care skills. Asked how they expected to achieve these results, most parents said they placed their faith and trust in NGOs while a few thought that the care the community and family members were providing would be sufficient. Parents who were receiving services and support became less concerned with finding a cure and were more likely to accept the child's condition and look for ways to respond to their needs.

Interviews with teachers found that the biggest challenge facing New Humanity CBR staff was teaching hygiene and health care and its importance to the beneficiaries and their parents. Most of the children with intellectual disabilities lived in very unhygienic and unsanitary conditions. All the children lived on the ground and had no access to safe water. Some mothers, who were in charge most of the time, were not strong enough to move their older son or daughter with disabilities to help them use the toilet. Teachers also expressed concern about the widespread practice of self-medication by parents, sometimes involving wrong or spurious drugs, in their desperate efforts to find partial relief for their child. The special needs teachers found also the tasks of caring for the children and getting parents to understand the importance of sending their child to school regularly as well as attending the parent training activities very challenging. The children's health and nutritional status was also a concern for the staff. Most of the concerns voiced by the teachers did not match those of the parents'. While parents worried about their child's future, the teachers, recognizing that poor living conditions might preclude the possibility of a future, were worried about the child's present. However, merely giving advice to parents without providing concrete alternatives or suggestions had not had much effect on changing parents' behavior and attitudes towards maintaining hygiene.

All the CBR teachers had completed between grade 9 and 12 of schooling and were more comfortable learning by imitation ("seeing and doing") than by reading the extensive material on disability developed by NGOs and other international institutions that was more easily available to them, probably since most of these materials are in English. However, the limited numbers of trained special education teachers in Cambodia and the expense of bringing in external or international consultants for training meant that opportunities for hands-on learning were few and far between, not to mention too short and often lacking in continuity.

5.2 Recommendations

We believe that the support provided by public institutions as well as the concern and support of the community have to increase gradually. Unfortunately, the notion of sustainability, at first glance, does not appear to be applicable to this sector in that all existing services are provided by NGOs and there is little monetary investment by the government. It is important to take specific steps towards reducing this heavy dependence on NGOs and increasing sustainability. First, we need to reinforce the quality of service of provincial hospitals and health centers, so service and responsibility provided by the NGOs will decrease progressively. Second, the role of the community has to be strengthened, so that the community can shoulder economically exceptional cases. To do so, villagers need to be informed about and become aware of intellectual disability, its causes, options and limitations. It is important to understand that families cannot be expected to take on the entire responsibility and concern for their child.

Based on the findings of this research, we present the following recommendations arranged according to four major categories.

5.2.1 Building information systems on intellectual disabilities

Family members of the children with intellectual disabilities should have more access to information on how to care and deal with their children's situation. The more parents are informed and instructed about their child's intellectual disability, the more parents feel involved and are eager to do something to help their child.

Children with intellectual disabilities need special care not only from government institutions or NGOs but fundamentally from their own family members. Thus, any provision of services for a child with intellectual disabilities must involve the community and the family, specially mothers and primary care-givers, who are the best vehicles for dissemination within the families. This information can include topics like:

- What is disability (intellectual disability) and its health and social implications.

- Kinds of intellectual disabilities, especially those common in the Cambodian context, and its particularities.
- Early prevention and detection as well as treatments possible, so parents can also be involve in physiotherapy and other specific therapies according to the disability.
- Basics of sanitation, safe water, and personal hygiene.
- Effects of self-prescription or self-medication.
- Educational options available and later possibilities for employment, as appropriate
- Legislative and policy mandates that relate to individual and parental rights and service provision.

- Dissemination and training about these topics should target all stakeholders, including not only parents, but teachers and doctors, towards the successful inclusion of children with disabilities, as mandated in the *Law on the Protection and the Promotion of the Rights of Persons with Disabilities.*
- The cultural approach should be considered in the dissemination of information and in trainings. Changes on language of disability might be the first step to transform the negative perceptions of people with intellectual disabilities. Therefore, terms to refer people with intellectual disabilities with less or no negative connotations should be popularized.

Because of deep rooted beliefs in animism and Buddhism, government, NGOs, and other institutions working in the field of intellectual disability should consider the cultural approach of families, especially in the countryside, respecting their way on how to perceive intellectual disability: causes, symptoms, and treatment. Caregivers must reflect on how this approach can help the incorporation of these individuals by redrawing/re-interpreting the boundaries between what is socially accepted and what is considered an anomaly.

It is important that professionals have a good understanding of families' perspectives and beliefs in order to provide services that are meaningful and responsive to their needs.

Service providers should stop trying to change people's traditional beliefs about causes of intellectual disabilities, but instead show an attitude of respect accompanied by more effective campaigns of information.

5.2.2 Building skills to work with people with intellectual disabilities

More programs and trainings should be developed and provided to school teachers that introduce them to special curriculum and techniques on how to teach children with intellectual disabilities. Thus, the more teachers receive specialized training and more parents can access auxiliary services in addition to an education, more children with intellectual disabilities will be sent to school.

There is a need to use a more systematic approach for developing a standardized curriculum and training for teachers to work with children with intellectual disabilities.

More health care providers need to be specialized on maternity care as well as on intellectual disability. Parents' efforts to seek help at public facilities should be encouraged through collaboration into attainable expectations, by building a common strategy between parents and health care providers.

The provision of health care in public institutions is still very precarious, due to the lack of qualified professionals for antenatal and postnatal care. Most health providers lack the capacity to detect early characteristics of intellectual disability. There is a need to train health providers to recognize early warning signs of disability, especially intellectual disability, towards reducing the long-term impact of the disability. Further, more qualified professionals are needed in rural areas, given that the majority of the Cambodian population lives there, so that families can access necessary services much more easily.

In the framework of a program for children with disabilities, each child with intellectual disabilities should be treated as unique. Professionals, families, and especially primary caregivers must be encouraged to improve the condition of children with intellectual disabilities.

It is important to emphasize to parents and professionals that no two children with intellectual disabilities, even those with similar conditions like Down syndrome, are alike, so that each child will be considered as unique and the disability does not become the defining feature of the child.

Parents should be encouraged to keep their child in good hygienic and sanitary conditions in the house. Parents will begin to see how their child can learn and interact if they are provided with an educational and rehabilitation program according to their capacities, and recognize the need to provide a stimulating environment for learning within the home as well.

Families should also be encouraged to share the responsibilities of looking after the child with intellectual disabilities so that this huge responsibility does not fall only the mother. Each member of the family needs to believe in the potential of their child with disabilities, brother or sister, so their situation can be improved.

Service providers, parents, relatives and the community in general must learn to recognize and advocate against acts of discrimination inside and outside their communities.

We do believe that, as in the case of special needs teachers of NH CBR centers, parents, relatives and community at large must learn to recognize and advocate against acts of discrimination inside and outside their communities, taking into account religious and traditional beliefs. Discrimination can only have a negative impact on the self-esteem and potential of these children.

Since there are parents of children with intellectual disabilities who are still seeking health care among traditional healers, government and NGOs working with the sector of intellectual disabilities must develop trainings to upgrade the knowledge of these traditional healers, consequently they can help parents with not only physical but also mental and emotional states.

5.2.3 Building common strategies of cooperation for a friendly environment in favor of people with intellectual disabilities

- Service providers must work more closely with parents not only by increasing and strengthening their awareness of the need for better health and hygiene at home, but also by identifying the barriers parents experience in maintaining these standards and mutually deciding on practical solutions towards achieving these goals.
- More CBR centers and/or activities should be established, so more families can receive services for their children with intellectual disabilities, and then parents can have more chances to generate income and eventually improve their family's livelihood.
- Parents and caregivers need professional and regular on-going assistance to ensure the well-being of children with intellectual disabilities. Thus parents should be encouraged to engage in discussions to share their fears and concerns for their child's future and then consider some practical solutions among the options that may be available.

Long-term or permanent contact with intellectual disabled children can eventually lead to exhaustion (burn out) not only physically but also psychologically. Parents, especially mothers, need counseling to process questions like: Why did this happen to me? What did I do wrong? Most of the suffering is rooted in guilt and deep self-rejection[22].

Another crucial matter that counselors should be aware of is that many parents may have different responses to their child’s disability. While many parents, community, and caregivers accept the child with intellectual disabilities with resignation, a passive attitude that does not lead to any effort for the improvement of the child's condition, our study showed that several parents also adopt a more dynamic attitude of "active acceptance" which goes beyond resignation. In this approach parents do not consider the disability of their child as a final situation and are willing to consider options towards improving the well-being of their child and, eventually, his/her full integration into society. Counselors

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[22] Henri Nouwen, The Road of Peace. 1999

can assist parents presenting the active acceptance attitude to continue in this direction by providing information about service options available and helping to change negative community attitudes. Counselors can assist parents presenting the resignation mode to move towards the active acceptance approach by explaining the potential for improvement in their child and helping the family to arrange that the child receive appropriate services towards this goal.

- Agricultural training to families, such as NH is providing, which helps to diversify the diet can improve the nutritional status of the child and benefit all family members as well. In some cases, people with intellectual disabilities can be also involved in these agricultural activities.
- Experiences of inclusive education and integrated class within the public schools should be implemented and expanded in each province.

It is extremely important that children with intellectual disabilities have the opportunity to be involved in the life of the school, near other non-disabled children. Policies regarding employment and vocational training for people with intellectual disabilities as stated in Chapter 7 of the Law cannot materialize if there is no access for children with intellectual disabilities to special education or training according to their capacities.

Mutual cooperation between government and non-government institutions must be supported and reinforced. On one hand, government must enact and enforce laws that benefit the sector, while, on the other hand, international agencies and NGOs should develop appropriate and adapted strategies in line with the administration's policies in favor of people with intellectual disabilities.

Some causes of intellectual disabilities are likely preventable. We need mutual cooperation between government and non-government organizations that can ensure more comprehensive coverage to provide preventive services to this sector of the population across all geographic regions in Cambodia, especially rural areas.

- The discourse on disability has to be more inclusive, highlighting not only issues relating to children with physical disabilities but also children with intellectual disabilities.
- Advocacy programs must be encouraged and supported, so public awareness about people with intellectual disabilities can be spread out throughout rural Cambodia. Thus dissemination of the 2009 *Law on the Protection and Promotion of the Rights of People with Disabilities*, which mandates that children with intellectual disabilities will have greater access to services, in particular, free consultation for health care is crucial. Steps to enable rural health care facilities to offer a qualified service or a system of referral should be taken.

The first step of this activity should be to start a campaign of awareness throughout the public schools. The first recipients of these activities should be the young generation. The Cambodian/World Day for Persons with disabilities (December 3rd) and Special Olympic Games (held in Phnom Penh) should be promoted more with a larger mass media coverage at provincial and national level accordingly.

Through their children and youth, communities can be encouraged to develop a friendly and inclusive attitude towards children with disabilities, especially those with intellectual disabilities. The more students learn about intellectual disability the better will be the conditions for future social integration.

5.2.4 Building a body of knowledge on intellectual disabilities

Further research should be done on the following issues:

- Situation of children with intellectual disabilities in the schools and how teachers are trained to deal with these particular situations.
- Impact of inclusive education for students with intellectual disabilities in Cambodia.
- Impact of other educational experiences like integrated classes for children with intellectual disabilities.
- Current level of knowledge and experience on intellectual disabilities of health providers in rural and urban areas.
- Perceptions of discrimination and exclusion relating to intellectual disabilities.

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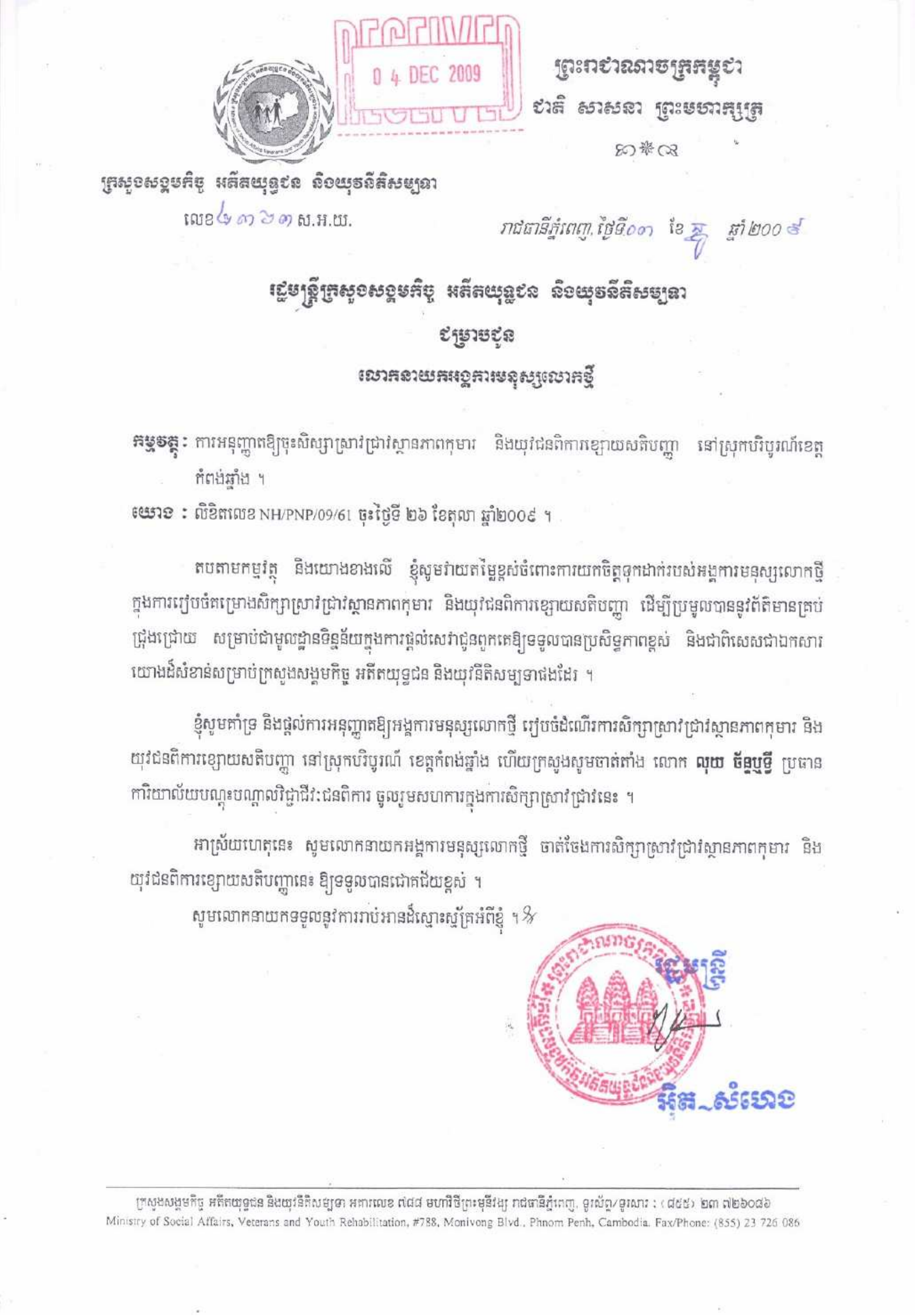
ANNEXES

ANNEX 1: SUPPORTING LETTER FROM MoSVY



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ព្រះរាជាណាចក្រកម្ពុជា
ជាតិ សាសនា ព្រះមហាក្សត្រ

ក្រសួងសង្គមកិច្ច អតីតយុទ្ធជន និងយុវនីតិសម្បទា
លេខ ៤៣២៣ ស.អ.យ.

រាជធានីភ្នំពេញ, ថ្ងៃទី០៣ ខែធ្នូ ឆ្នាំ២០០៩

រដ្ឋមន្ត្រីក្រសួងសង្គមកិច្ច អតីតយុទ្ធជន និងយុវនីតិសម្បទា
ជម្រាបជូន
លោកនាយកអង្គការមនុស្សលោកថ្មី

កម្មវត្ថុ : ការអនុញ្ញាតឱ្យចុះសិក្សាស្រាវជ្រាវស្ថានភាពកុមារ និងយុវជនពិការខ្សោយសតិបញ្ញា នៅស្រុកបរិបូរណ៍ខេត្តកំពង់ឆ្នាំង ។

យោង : លិខិតលេខ NH/PNP/09/61 ចុះថ្ងៃទី ២៦ ខែតុលា ឆ្នាំ២០០៩ ។

តបតាមកម្មវត្ថុ និងយោងខាងលើ ខ្ញុំសូមវាយតម្លៃខ្ពស់ចំពោះការយកចិត្តទុកដាក់របស់អង្គការមនុស្សលោកថ្មី ក្នុងការរៀបចំគម្រោងសិក្សាស្រាវជ្រាវស្ថានភាពកុមារ និងយុវជនពិការខ្សោយសតិបញ្ញា ដើម្បីប្រមូលបាននូវព័ត៌មានគ្រប់ជ្រុងជ្រោយ សម្រាប់ជាមូលដ្ឋានទិន្នន័យក្នុងការផ្តល់សេវាជូនពួកគេឱ្យទទួលបានប្រសិទ្ធភាពខ្ពស់ និងជាពិសេសជាឯកសារយោងដ៏សំខាន់សម្រាប់ក្រសួងសង្គមកិច្ច អតីតយុទ្ធជន និងយុវនីតិសម្បទាផងដែរ ។

ខ្ញុំសូមគាំទ្រ និងផ្តល់ការអនុញ្ញាតឱ្យអង្គការមនុស្សលោកថ្មី រៀបចំដំណើរការសិក្សាស្រាវជ្រាវស្ថានភាពកុមារ និងយុវជនពិការខ្សោយសតិបញ្ញា នៅស្រុកបរិបូរណ៍ ខេត្តកំពង់ឆ្នាំង ហើយក្រសួងសូមចាត់តាំង លោក **លុយ ច័ន្ទឫទ្ធី** ប្រធានការិយាល័យបណ្តុះបណ្តាលវិជ្ជាជីវៈជនពិការ ចូលរួមសហការក្នុងការសិក្សាស្រាវជ្រាវនេះ ។

អាស្រ័យហេតុនេះ សូមលោកនាយកអង្គការមនុស្សលោកថ្មី ចាត់ចែងការសិក្សាស្រាវជ្រាវស្ថានភាពកុមារ និងយុវជនពិការខ្សោយសតិបញ្ញានេះ ឱ្យទទួលបានជោគជ័យខ្ពស់ ។

សូមលោកនាយកទទួលនូវការរាប់អានដ៏ស្មោះស្ម័គ្រអំពីខ្ញុំ ។

រដ្ឋមន្ត្រី

អ៊ិត_សំហេង

ក្រសួងសង្គមកិច្ច អតីតយុទ្ធជន និងយុវនីតិសម្បទា អគារលេខ ៧៨៨ មហាវិថីព្រះមុនីវង្ស រាជធានីភ្នំពេញ, ទូរស័ព្ទ/ទូរសារ : (៨៥៥) ២៣ ៧២៦០៨៦
Ministry of Social Affairs, Veterans and Youth Rehabilitation, #788, Monivong Blvd., Phnom Penh, Cambodia. Fax/Phone: (855) 23 726 086

Unofficial Translation of Supporting Letter from MoSVY

KINGDOM OF CAMBODIA
Nation Religion King

* * *

Ministry of Social Affairs, Veterans and
Youth Rehabilitation
No. 2363 MoSVY

Phnom Penh, December 03, 2009

Minister of Social Affairs, Veterans and Youth Rehabilitation

To:

The Country Director of New Humanity

Subject: Approval to conduct a research on the situation of children and youth with intellectual impairment in Boribor District, Kompong Chhnang Province

Reference: Letter No. NH/PNP/09/61, dated 26th October 2009

In reference to the aforementioned, I would like to express my highest appreciation to New Humanity for conducting this research on the situation of the children and youth with intellectual impairment, which aims to collect valuable information and database in order to provide services to this sector more effectively. This document might become a vital reference for the Ministry of Social Affairs, Veterans and Youth Rehabilitation as well.

I would like to support and give authorization to New Humanity to conduct this research on the situation of children and youth with intellectual impairment in Boribor District, Kompong Chhnang Province, and the ministry is pleased to appoint Mr. Lu Chanrithy, Chief of Office of Vocational Training for People with Disabilities, to join this research in cooperation with New Humanity.

In according with what has been said, I wish the Country Director of New Humanity a successful research activity on children and youth with intellectual impairment.

Please accept with my sincere regards.

The Minister

(Signature and stamp)

ITH SAMHENG

ANNEX 2: QUESTIONNAIRE

Daily life of People with Intellectual Impairment in Cambodian Rural Areas
- A Case Study in Boribor District, Kompong Chhnang Province –

Questionnaire Guideline

In-depth interview for Parents of the children with Intellectual Impairment

(4 families receiving the services and 4 families not receiving the services)

INTERVIEW NAME : ____________________________________
WHEN (dd/mm/yy) : / February / 2010
WHERE : ____________________________________
____

BACKGROUND OF IMPAIRMENT

A_1. Do you know what kinds of impairment?

A_2. What are the problems of your child have?

A_3. As your thinking, what the main cause of the problem is?

A_4. Could you please tell me about your or your wife's pregnancy story? How many children in your family? How old are they? *(Total born and total surviving)*

A_5. Who noticed your problems' child? How? When did you notice that your child have the problem?

A_6. What were problems that you noticed?

- How did you feel when you notice these problems?
- How did your spouse/husband/wife take action when you told them about these problems?
- How did you feel when they said this?

A_7. After you knew that your child had problems, what did you do to help your children?

- What happened next? What was the age of the child when you first noticed with the problems?

- What was the age of the child when you took them to the doctor or Khmer traditional healers?
- When you took them to Khmer traditional healers, what did they say? What did they do to treat your children? Did it help them?

A_8. Did your children ever go to school? If not, why?

A_9. What are the daily challenges in raising your child with intellectual impairment?

- What are tasks that your children can do by him/herself?
- Who taught him how to do these tasks?
- What are tasks that your children need the assistance? For example dressing, eating, bathing...
- Who provides these assistances?
- If mother/father/siblings has to care the children and cannot go to school, earn money, help with the household tasks, etc?

A_10. How do you feel about daily care to his/her health condition?

- Does the child need medical care for his/her health condition?
- What are the costs of this medical care?
- Can you afford these costs?
- How are you or your family getting medical care for your child?

A_11. Are you receiving some kinds of support to raise your child with impairment? If yes, can you details about these supports? (For example, medical care or treatment, income generations, community-based rehabilitation, parent training, education for the child transportation, other financial assistance)

DISCRIMINATION ON CWII

The purpose of my next question is to learn about attitudes towards children with intellectual impairments. We want to know; what are the beliefs of people about the children with intellectual impairments, especially if these are negative beliefs. For example, in one village in another province, the villagers stopped visiting one family who had a child with an intellectual impairment. We would like to raise awareness about children with intellectual impairments and help to change these attitudes.

A_12. Have you and your child ever faced discrimination due to his/her intellectual impairment?

A_12a. If yes, where? How you and your child were discriminated? Can you give any example?

A_12b. If not, why do you think people do not discriminate you and your child?

- Overall, would you say that people are generally accepting of your child or not?
- If they use pity words, please ask what do they mean about these words?

THE FUTURE PLAN BY PARENTS OF CWII

A_13. What are your concerns or fears for your child in the future?

A_14. What are your wish/expect for your child with intellectual impairment?

- What do you hope that they will be able to learn in the next one year?

A_15. How can these expectations be achieved?

ANNEX 3:
SITUATION OF CHILDREN WITH DISABILITIES IN KOMPONG CHHNANG PUBLIC SCHOOLS
Study Report - July 2010

Identification process

This survey was an attempt to identify the prevalence of children with disabilities in public schools located in Boribor and Kompong Chhnang district. This assessment was conducted by New Humanity's M&E coordination team in close collaboration with the village leaders, school directors, and teachers. In order to identify children with disabilities as accurate as possible the data collection process was done in two steps. The first step was conducted by the school principal and the second step was conducted by New Humanity (NH) team in order to collect more technical information about the disability and its categorization.

In the first step, our program officer informed to local authorities and school directors about the purpose of the survey, and then the method of data collection was explained. The criteria used to categorize the disability were the one given by the MoSVY. Once these forms were filled up by the School principal in collaboration with our staff, the forms were gathered and recorded into a file.

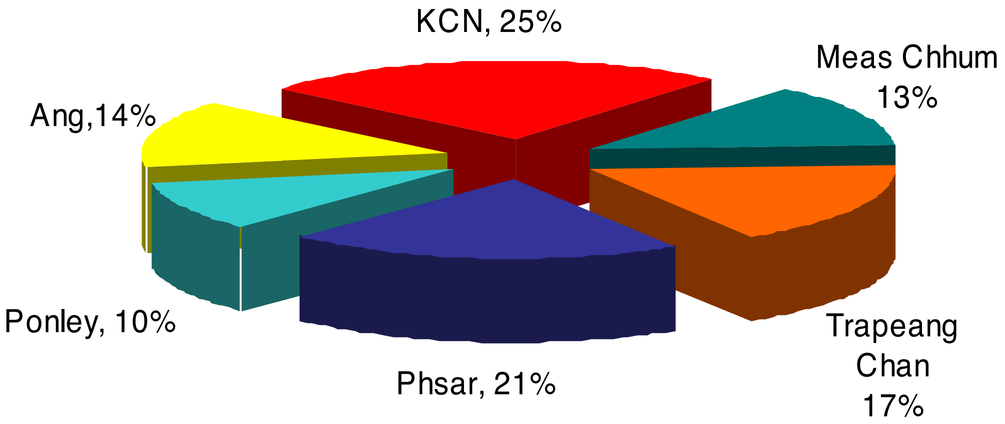
In the second step, our staff took all the information collected and went back to the schools to re-confirm the figures and condition of the 507 children identified as children with disability. The staff used the same form including the disability criteria; however, the difference was that our staff spends more time on face to face interviews and observation to establish a closer diagnosis of their condition. As a result of this second step we could confirm the presence of only 118 disabled out of 507 at the beginning; it represents the 0.5% of the total number of students in public school within Boribor and Kompong Chhnang Province. It is understandable that for lack of experience and limited knowledge on disability, school principals were not accurate in their assessment and identification. Of this 88 students with disability (0.7%) were detected in 28 schools in Boribor out of 13,021 students. And the other 30 children with disabilities (0.3%) were found out in 7 schools in Kompong Chhnang district out of 9,999 students.

In order to facilitate the description of data, schools were grouped in 5 clusters according to its geographic location. The clusters were: Meas Chhum, Trapeang Chan, Phsar, Ponley, Ang, and the 7 schools in Kompong Chhnang district were grouped only in one cluster.

Findings of the survey

The prevalence of children with disability by location, according to our findings, is as follows: 13% of students with disability were identified in Meas Chhum, 17% in Trapeang Chan, 21% in Phsar, 10% in Ponley, 14% in Ang, and 25% in Kompong Chhnang Cluster.

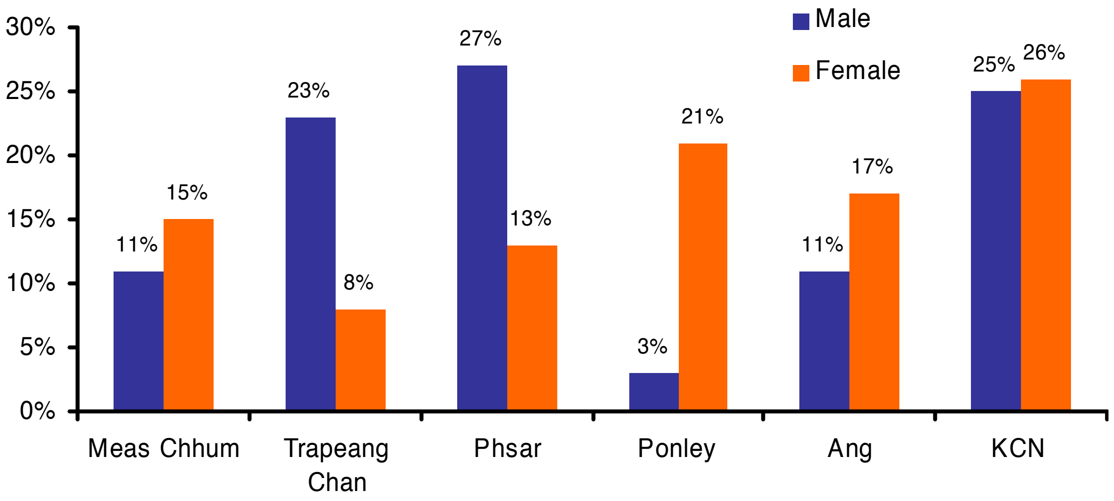
Figure 1: Distribution of Students with Disabilities by Cluster (n=118)



Sex and age of students with disabilities identified

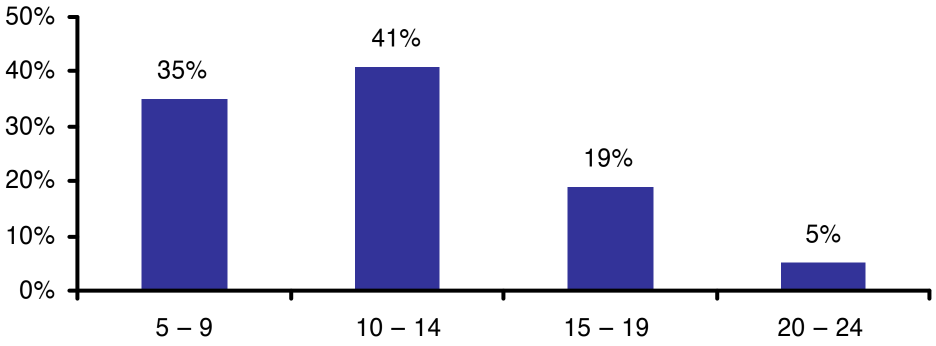
Among all the students with disabilities identified, 60% were male students and only 40% were female. The figure below show that the variation between male and female is slightly different in Kompong Chhnang cluster, but it is vastly different in the other five clusters in Boribo district.

Figure 2: Sex of Students with Disabilities by Cluster (n=118)



The range of age identified was 76% of students with disabilities aged from 5-14 years old and only 24% aged from 15 to 24 years old. It is interesting to see that most of the students with disabilities found were younger than 15 years old, this may indicate that the older the children are the less are the opportunities to continue their studies either because their disability has developed in gravity or family does not find practical reasons to send their child with disabilities to schools within a frame of uncertainty. However the first reason might be the closest to reality, given that higher grades of education increase the challenges and the physical and intellectual efforts.

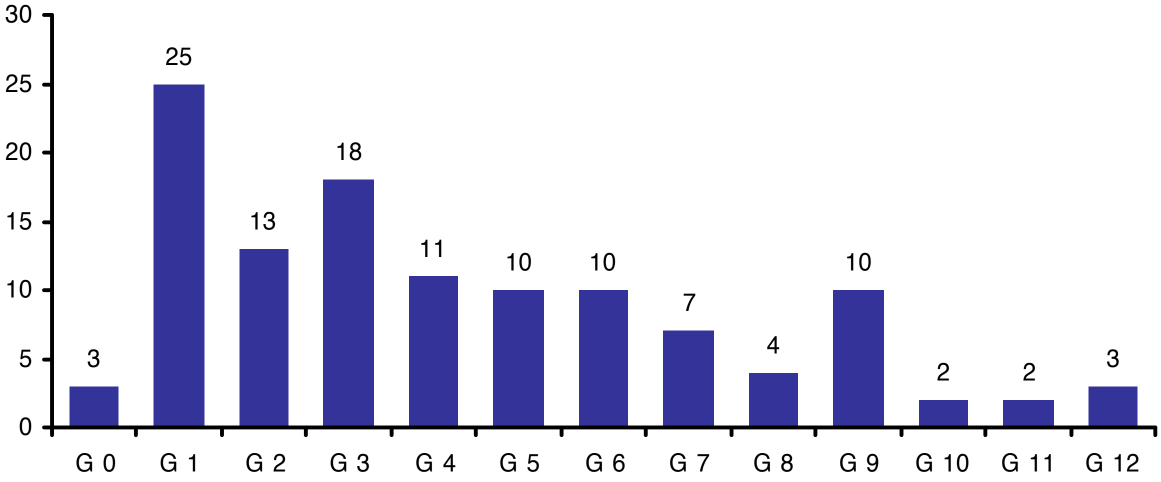
Figure 3: Age Group (n=118)



Educational attainment

The higher prevalence of very young children is confirmed in the graphic below showing 87 students with disabilities (74%) studying in primary schools, of which 25 students with disabilities were studying in Grade 1, 13 in Grade 2, 18 in Grade 3, 11 in Grade 4, 10 in Grade 5, and 10 in Grade 6. By contrast only 7 out of 118 disabled students (6%) were studying in high school, and 3 children were studying in Grade 12. Another reason to explain the absence of a greater number of students in high school is the lack of teachers able to adapt their teachings according to the student with disabilities' needs. It is evident that for some students in high school it is hard to follow the same rhythm of the other students due to their impairment. It does not mean that they cannot learn by contrary is only a matter of putting the student on an equal condition with the rest of their classmates.

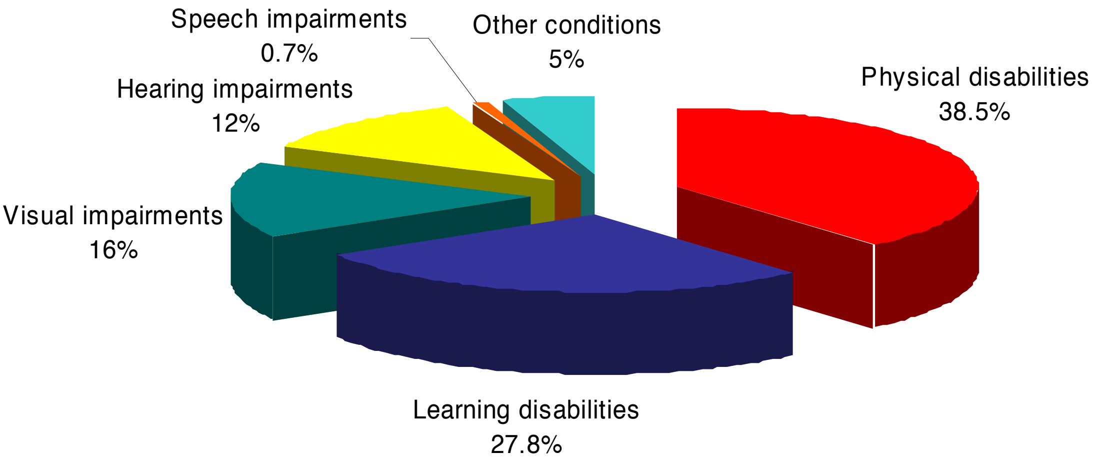
Figure 4: Educational Attainment (n=118)



Type of disabilities

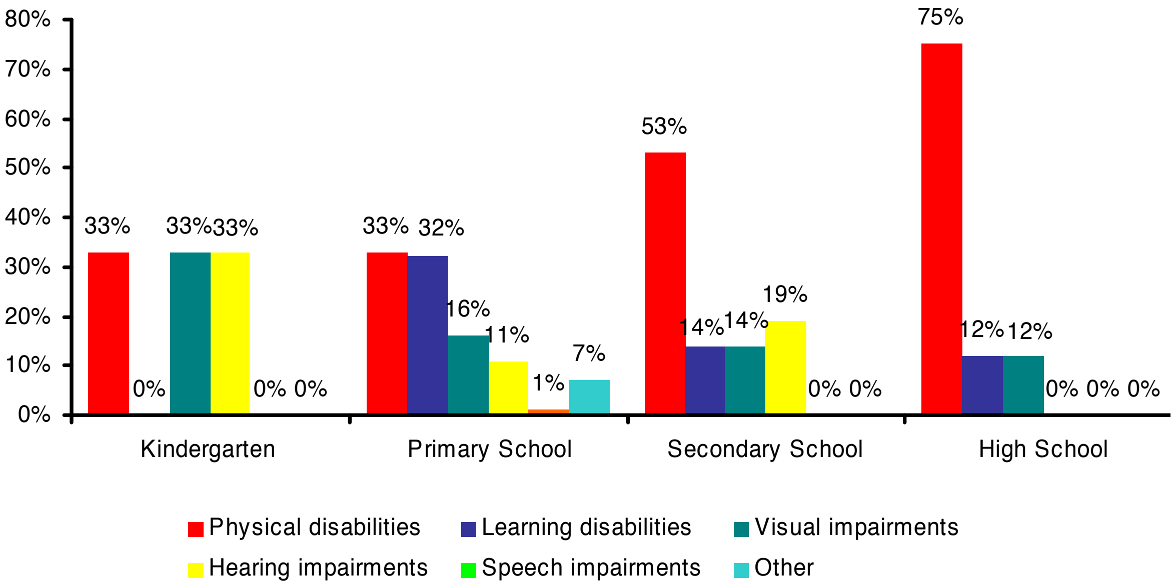
According to the findings, 20 out of 118 students with disabilities had two kinds of impairments and only 1 case had 3 kinds of impairments. In the graphic below, the total number of students with disabilities was allocated within the following categories: students with physical disabilities (38.5%), students with learning disabilities (27.8%), with visual impairment (16%), with hearing impairments (12%), with speech impairments (0.7%), and other disabilities (5%).

Figure 5: Type of Disabilities (n=118)



It is interesting to note that the highest proportions of students with disabilities in the high school have physical disabilities (75%), while only 12% of them have learning disabilities, and 12% visual impairments. Moreover, the children with physical disabilities also have highest proportion in the secondary school (53%), in contrast with 14% of children with learning disabilities, 14% with visual impairments, and 19% with hearing impairments. Contrastingly, the highest proportion of students with disabilities in primary school have learning disabilities (33%), and 32% of them have physical disabilities, while children with visual impairments represents only 16%, children with hearing impairments represents 11% of the population observed, and only 1% of children with speech impairments, while other children (7%) present other conditions that hinder their studies.

Figure 6: Type of Disabilities by Educational Attainment (n=118)

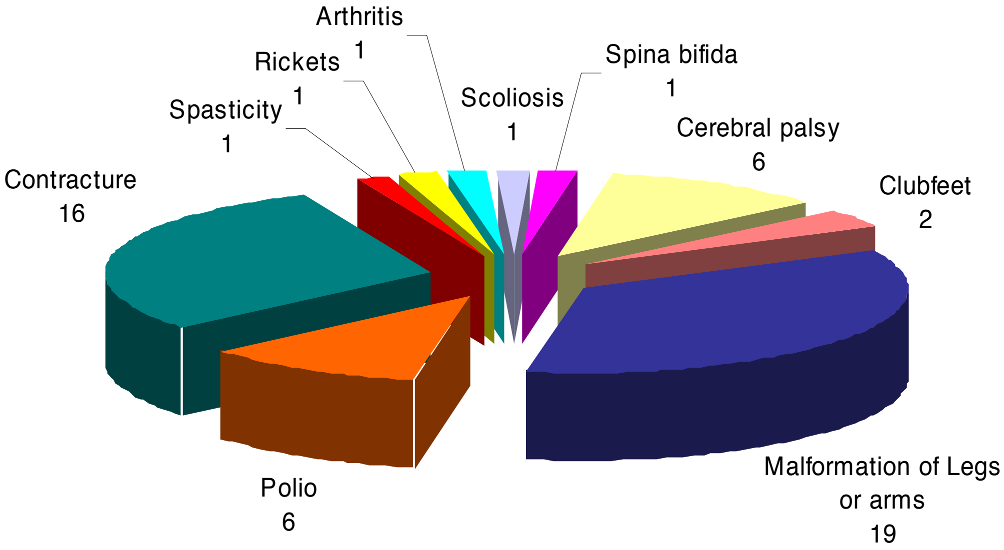


According to the figures above, we can state that children with Physical disabilities are more likely to attain higher education than those children with Learning disabilities.

Physical disabilities

Regarding students with physical disabilities, our findings show the following results: 19 of them have malformations; of these 9 out of 19 students suffer of limbs malformation, while 4 have malformation only on their hands, and 6 have malformation only on their legs. It was also found problems of contracture, for instance we found 12 children with contracture in their legs and the other 4 contracture in the arms. The prevalence of students with other kind of disabilities is less important than the first two aforementioned. These other disabilities includes: polio, cerebral palsy, clubfeet, rickets, arthritis, spasticity, scoliosis, and spina bifida.

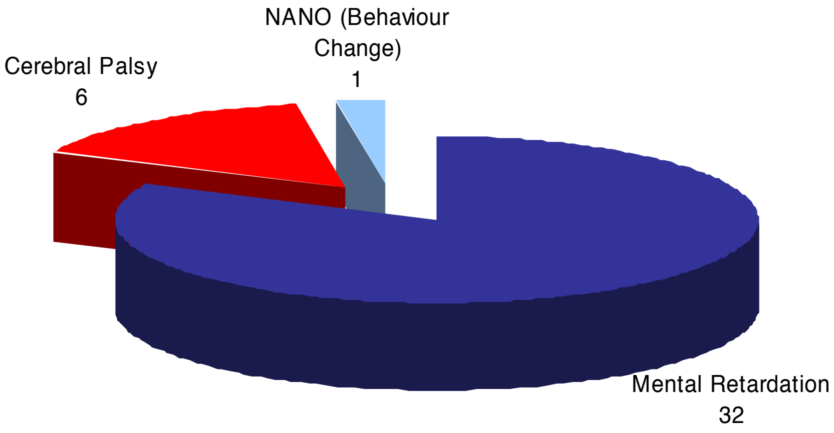
Figure 7: Type of Physical Disabilities (n=54)



Learning disabilities

Some of the children (27.8%) identified have some kind of learning disabilities. According to the observations on the field it was difficult to find out with accuracy the kind of impairment but it was clear that because of their condition the process of learning was slower compare to the other students.

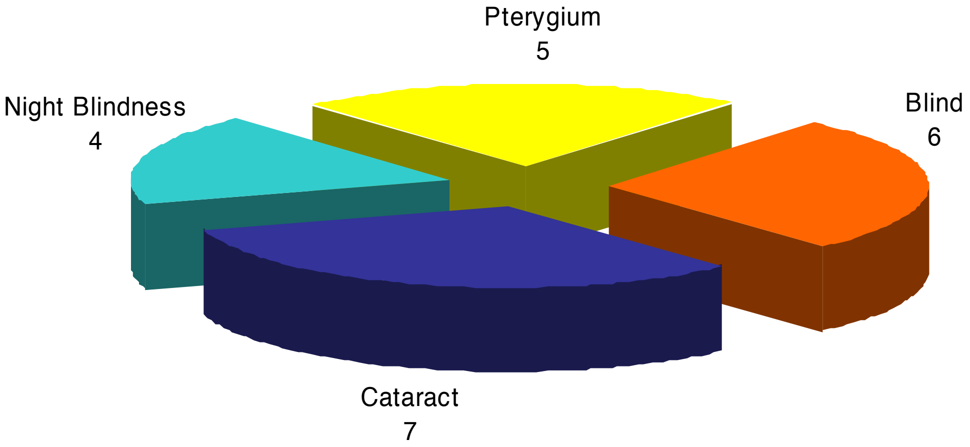
Figure 8: Type of Learning Disabilities (n=39)



Visual disabilities

Among those who have visual impairments, 6 were blind, 4 students had problems of vision in dim light (night blindness), 5 had some kind of membrane growing on the eye obstructing their vision (Pterygiums), and 7 had Cataract.

Figure 8: Type of Visual Disabilities (n=22)



Hearing and speech disabilities

Among those children who suffer some kind of hearing impairments, all of them were deaf. Additionally, we identified only one student who has speech impairment because of clef lips. Besides, we also found several children have other conditions of impairment as: hydrocephaly, poliomyelitis, lipoma, post of TB, hernia, and heart problem. It was difficult to establish the level of impairment that these children were facing out at school, but is evident that they have serious problems to follow the lessons given by the teachers.

Challenges and needs of students by type of disability

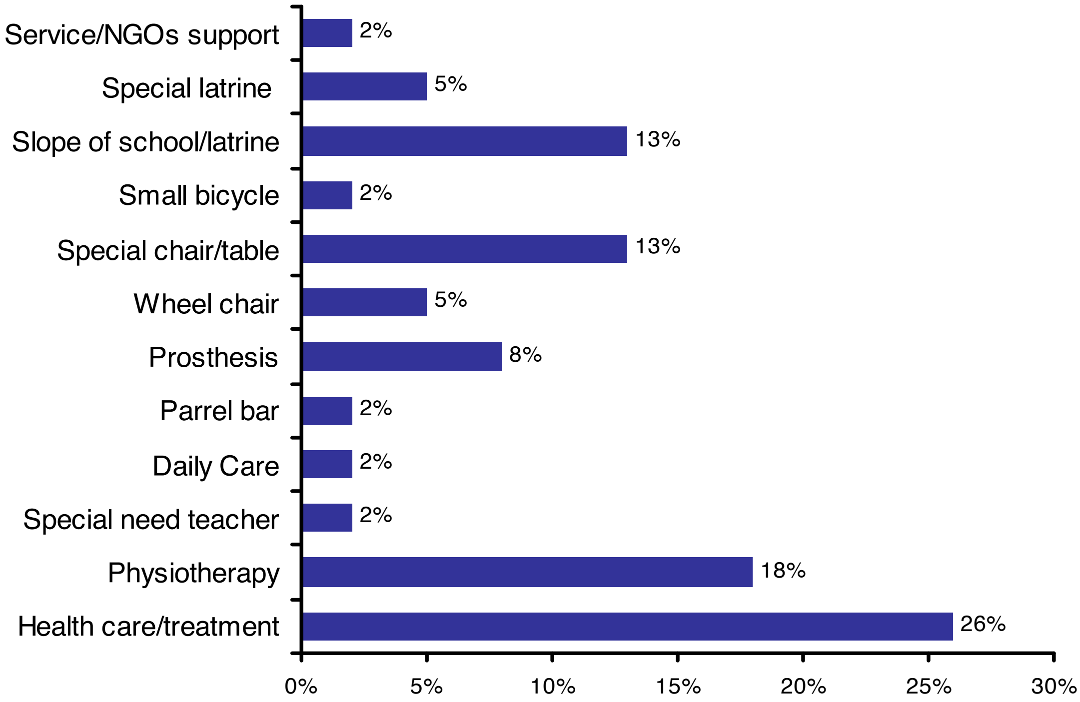
Physical disabilities

The students with physical impairments have hard time to move and hold objects during the class. According to our observation on the field, students who have physical malformations in the arms and hands write with great difficulty. Then, they have to write slowly, and it is tough for them when the time of dictation or written assignments comes, they found themselves in complete disadvantage compare to the other students. On the other hand, for students who have malformation in their legs, the difficulties are less due to their impairment reduces only their mobility, for them there is no problem in follow the process of learning.

However, the problem of mobility is affecting on attendance rates, due to some of the students relies on others to move from one place to another, especially for those living far from school. Some of them already count with the help of wheelchair to go to study. Nonetheless, by experience, we observed that these children are very motivated for learning; most of the teachers expressed to us their admiration for the outstanding effort of these students.

Students, who have rickets, clubfoot, Arthritis, Spina bifida, and Scoliosis, were also included within this category of physical disability. Most of them have problems of mobility and dexterity of their limbs rather than problems related to intellectual impairments.

Figure 9: Needs of Students with Physical Disabilities



According to the survey the identified needs for children with physical disabilities are focused especially in 2 items: health care and physiotherapy. Both needs are possible to tackle with adequate actions, and especially with the mobilization of schools, community, and other organizations that can provide these services. In the graphic above we can also observe other needs identified that underline especially the need of instrumental support to facilitate mobility and autonomy of children.

- **Learning disabilities**

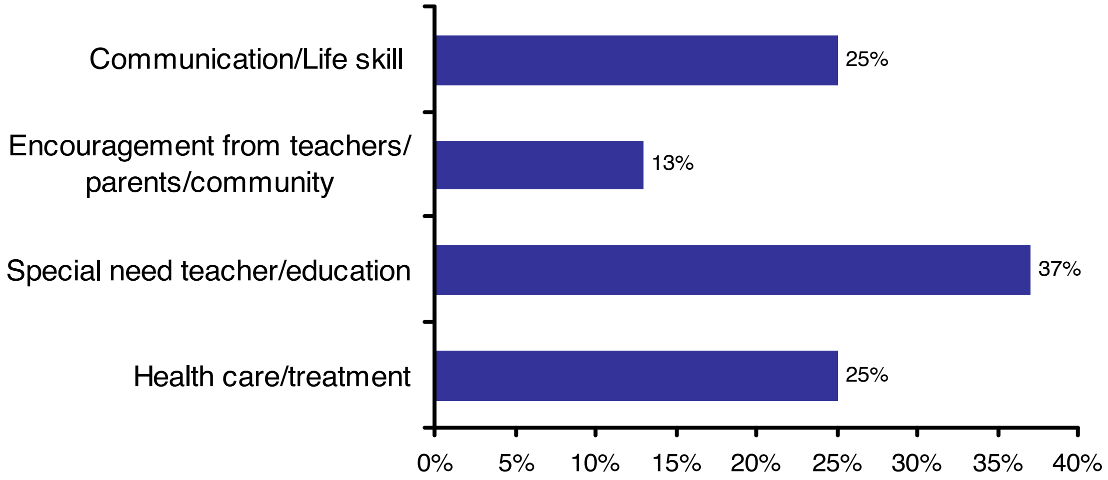
Some of the students identified (27.8%) have different problems on learning. Because of these problems on understanding, processing and retention, of what is taught by the teacher, repetition grade, in those children, is highly expected. As the risk of repetition rate is high, in the case of these students, the risk of dropout is also higher, thus the majority of these children abandoned school before Grade 6. Nonetheless, the causes of dropout depend on various factors as the kind of disability, gravity of the disability or health condition, and living condition of the family. During the observation on the field it was observed that although the quality of performance of these children were lower compare to other students, teachers use to encourage them to come to school.

Children with this kind of disability feels uncomfortable towards their classmates, difficulty in communication, speech, or whatever the problem is, they feel sometimes ashamed the reason why they prefer to retreat or withdraw from the group, to isolate themselves.

All these children sometimes feel discouraged, a feeling that drives them to stay at home rather than go to school. Most of these students are often absent from school.

The needs identified for these children refers especially to the possibility of adjustments and adaptations within the school, classroom and during the teaching. Perhaps the most important need identified is the lack of special education as: additional support for these children, adjustments such as additional time, individual assessment, more breaks, etc. Besides they need more control on their health condition and especial training according to the disability e.g. communication and life skills.

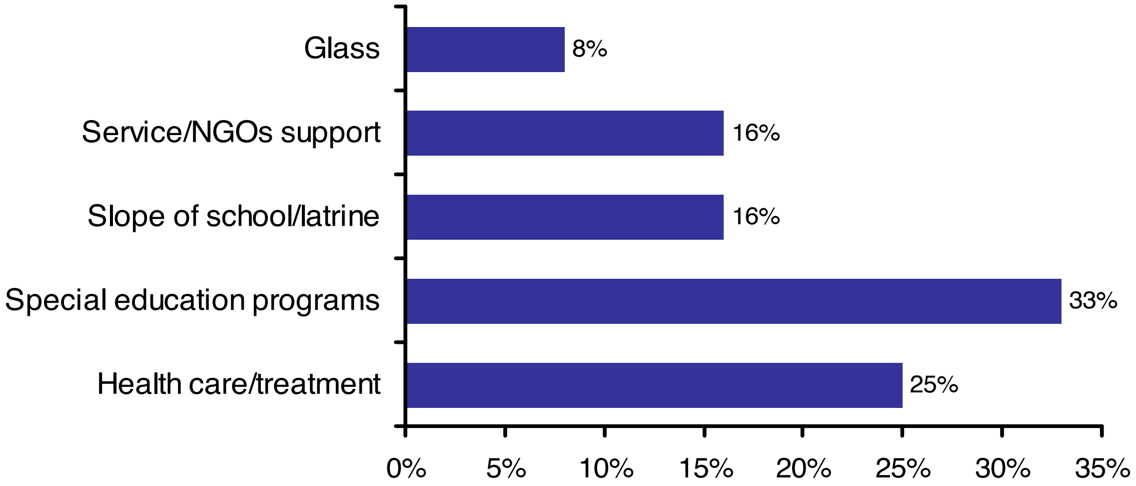
Figure 10: Needs of Students with Learning Disabilities



- **Visual disabilities**

In the public schools visited, does not exist any adaptation or special education for people with vision problems. The most common action is just to re-locate these children in the front row to facilitate their sight towards the blackboard. In some cases their vision is affecting somehow the speed in writing and reading, but teachers do not seem interested in using larger fonts for materials given to them, or adjusting the lighting of the classroom, or encourage verbal answers.

Figure 9: Needs of Students with Visual Disabilities



According to the graphic above, the common needs of students with visual impairment (33%) are special education program/teachers, followed by health care as in the other cases.

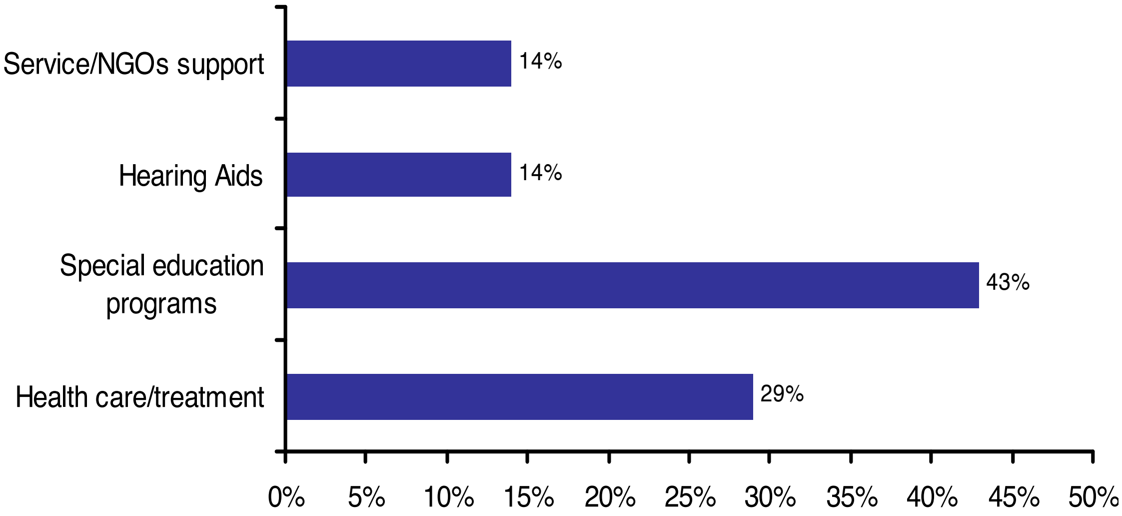
Hearing and speech disabilities

Among the students with hearing impairments there is 88% of them (15 out of 17 disabled) who are unable to speak properly. In these cases parents are not so much eager to send their children to school, they are afraid from the attitude and behavior of the other students, they think their children can be hurt or hit by the teacher or other classmates because of their slow learning.

Since there are not adjustments for teaching these children with hearing and speech impairments, they have to try to read the mouth of the teacher or understand the teachers' gestures. It is really hard for these children attend the school in these conditions. Ideally it should be important to implement especial education for these children in this geographic area without having to bring them to the cities far from their families. Because of their vulnerable condition they feel much attached to the members of their family and separation is not suitable.

According to the findings, the majority of student's needs with hearing impairment are special education program/teacher (43%). In case of one child with clef lips, the need is surgical intervention.

Figure 9: Needs of Students with Hearing Disabilities



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