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FAMILY ADAPTATION TO DEVELOPMENTAL NEEDS OF THEIR CHILDREN WITH MULTIPLE DISABILITIES: A COMPARATIVE ASSESSMENT STUDY OF SOME SWEDISH AND CAMEROONIAN FAMILIES

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Abstract:
This study assesses, in a comparatively perspective, how some families adapt to daily routines of the developmental needs of their children with multiple disabilities in order to enhance their wellbeing and learning. The study sampled (N=20) parents from 10 families in Cameroon and Sweden using the mixed method approach to data collection and analysis. Findings reveal commonalities in family adaptation to their children's health condition through: sacrificing extra time; rescheduling working hours; adjusting income, expenditure and plans; exploiting the available social support resources to meet the children's special developmental needs. In addition, since parents perceive multiple disabilities as a critical health condition, they maximize the scope of support activities to enhance child development. In distinction, Cameroonian nucleus families are structurally larger in size than Swedish. Functionally, the former is dependent upon and interacts with extended family members while the latter makes use of outsiders ranging from professionals to pets for support services. In child functioning, children in the standardized monolingual society of Sweden change key communication partners indiscriminately whereas those in the multilingual society of Cameroon permanently cling to one or few partner(s) influential in enhancing their development. In conclusion, the study recommended that parents should be given more professional help and voice in policy making regarding the support of their children with multiple disabilities.

Keywords: family adaptation, multiple disabilities, developmental needs, social support network, communication partners

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1. Introduction

Family adaptation to the developmental needs of their children with multiple disabilities means the strategies and procedures parents use to cope with the task of providing daily health care, social support and education to their children with co-occurring health conditions. Since the family is the smallest and the most indispensable unit of the society, the challenges it encounters in raising and supporting the development of such category of children has become the pre-occupation of institutions, scholars, researchers, national systems and the international community. Hence, the discourse of family adaptation to multiple needs of such vulnerable children is explicable when disability is conceptualised as a condition underpinned by bi-directional interaction between personal barriers (biological factors) and environmental barriers (ecological factors) that need to be replaced or reduced with personal and environmental facilitators (Disability International, 1981; WHO, 2003) in order to enhance their positive development in institutional, community and society settings.

According to WHO (2019) one billion people, or 15% of the world's population, experience some form of disability. Global awareness of disability-inclusive development is increasing. The UN goals and proactive support agencies including the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UNHR, 2010; Schulze,2010), the Universal Declaration of Human Rights, UNESCO, UNICEF, WHO and UNDP promote the full integration of persons with disabilities in societies (WHO, 2019) alongside other issues of national development. Despite these efforts, there are still numerous challenges especially for families raising children with multiple disabilities because of their state of vulnerability. Consequently, within the last few decades, the modern approach to intervention and support service delivery to such category of persons has become multidisciplinary in nature. It integrates health care, psychological, social and educational support services to enhance their day to day wellbeing and functionality. These family-based services also entail rehabilitation and acquisition of daily life skills delivered from early childhood to enhance their positive development towards adulthood (Disabled Peoples' International, 1981; International Disability Alliance, 2010) and prospective community independent living (Ratzka, 2003). Besides these aforementioned international community endeavours, the effects of globalisation through research, professional and cultural exchanges in our village planet have all been revolutionary forces in enhancing societal positive perception of, and attitude towards the disabled, adults and children alike in the society especially in family settings.

In order to understand family daily routine task load in handling children with multiple disabilities, it is worth understanding the meaning of disability. It is generally defined as a functional limitation that interferes with a person's ability to walk, hear, talk, learn, work among others. It is also referred to as physical, mental or sensory (visual/hearing) impairment which has substantial and long-term adverse effect on a person's ability to carry out normal day to day activities (Disability Act 2001 and Disability Discrimination Act of 1995). According to the overview of the WHO assessment frame on the severity of impairment, besides the afore-mentioned categories, disability may also include behavioural/emotional, speech/language (communication), mental, physical and sensory disabilities or co-morbidity of any of these health conditions. The WHO assessment frame of International Classification of Functional Disability and Health (ICF) (WHO, 2003) explains that the functional ability of the disabled may vary in respect to the intensity or degree of severity of the difficulties encountered continuously within the next 30 days non-stop and/or beyond. The disability qualifier or extent of impairments (degree or severity of disability) is as follows:

- **No impairment** means the person has no health condition or difficulty;
- **Mild impairment** means a problem that is present is less than 25% of the time, with an intensity a person can tolerate and which happens rarely over the last 30 days and/or beyond;
- **Moderate impairment** means that a problem that is present is less than 50% of the time, with an intensity, which is interfering in the persons day to day life and which happens occasionally over the last 30 days and/or beyond;
- **Severe impairment** means that a problem that is present is more than 50% of the time, with an intensity, which is partially disrupting the persons day to day life and which happens frequently over the last 30 days and/or beyond;
- **Complete or profound impairment** means that a problem that is present is more than 95% of the time, with an intensity, which is totally disrupting the persons day to day life and which happens every day over the last 30 days and/or beyond;
- **Multiple or complex impairments** means that there is co-morbidity or co-occurrence of more impairments or disabilities, (for example, deafness and blindness are referred to as blindness) (WHO, 2003). Thus, multiple disabilities means a combination of any two from 1 to 4 above, for example, a person may have mild mental plus severe hearing impairments or disabilities.

After formal assessment, the degree of impairment of the disabled usually affects the nature of their intervention or support activities in family, institutional and community settings.

Historically, the disabled have gloomy stories over the past centuries in different societies the world over: from being considered as human embodiment of evil spirits usually thrown in the evil forests and rivers in some African and Asian societies to being euthanized, used as street clowns and court entertainers, victims of Eugenic programs in some European and North American societies to when they started fighting for their rights across the globe over the past five decades (Clapton, & Fitzgerald, 1997; Union of the Physically Impaired against Segregation, 1976; Disabled Peoples' International, 1981; International Disability Alliance, 2010). Throughout 20th century the developmental mile stones of shift in practice and attitude towards the disabled in the US, for example, that has influenced global practice of support services, was characterised by four labelling stages. Firstly, ***"forget and hide"*** in early 20th century was when persons with significant disabilities were kept out of the public view or hidden in the dark room by their families. Secondly, ***"screen and segregate"*** in the 1950's and 1960's was when such categories of persons were isolated in residential homes. Thirdly, ***"identify and help"*** in the 1970's was when intervention and support services were provided in integrated settings. Finally, ***"educate and include"*** as from the 1980's onward, was when the target of service provision has been to contain disabling conditions, to prevent the occurrence of disabilities/disability related health conditions and to empower families with children with such conditions (Gartner and Lipsky, 1987)**.** Thus, over the past six decades, beginning with legal reforms in some countries of North America and Europe (Education for All Handicapped Children Act, 1975; Warnock Report 1978) and, with the influence of the UN and its international development agencies, there have been gradual global changes in the general perception of and attitude towards the disabled. The United Nations Convention on the Rights of the Child (UN, 1989), the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006), the UN Salamanca Statement of inclusion (UNESCO, 1994) and the UN commitment to equity and inclusion in education (UNESCO, 2019), among others, the whole world has been gradually involved in issues of wellbeing, inclusion, learning and development of the disabled in different settings of the society system through community-based rehabilitation centres, educational institutions and specialised medical establishments while using family members and caregivers as significant contacts in support service delivery.

Generally, support services for the disabled has been focused on special needs education, health care and psychosocial support assessment for preventing risky situations, overcoming developmental challenges and improving upon the wellbeing and learning conditions of children with diverse categories of disabilities. Hence, this agenda has been the preoccupation of policy makers, researchers and practitioners in most societies the world over. In the area of multiple disabilities, especially developmental delays, most research and clinical interventions have been oriented towards health, communication and self-help functional skills.

This paradigm shift indicates that since the disabled child doesn't live in isolation, the supportive environment, both the proximal (family, significant persons and objects) and the distal (community members and resources) play influential role in child's development (Bronfenbrenner, 1979; Guralnicks 1997; Shonkoff & Philips, 2000; Almqvist, 2004). Consequently, early interventionists consider the family as an integral part in the assessment process for intervention design, planning and implementation (Simeonssons, 2002; Simeonssons & Rosenthal, 2001; Trivette, Deal, & Dunst, 1986). This explains why the family centred approach to early childhood intervention is the most widespread form of practice nowadays (Björck-Åkesson, Granlund & Simeonssons, 2000; Walsh, 2002; Harbin, McWilliam & Gallagher, 2000; Africa Early Childhood Care and Development Initiative, 2010; European Association of Service Providers for Persons with Disabilities-EASPD, 2016; European Agency for Development in Special Needs Education, 2005).

In North America, the United States for example, the federal mandate requires that early intervention services should incorporate Individualised Family Service Plans (IFSPs) for children in their early years, plus Individual Education Programs (IEPs) for children of age range between 3 and 5 years (Schuck & Bucy, 1997; Johnson, McGonigel & Kaufmann, (1989). In Canada, the Community Action Program for Children and Families assumes such responsibilities at all provincial and local levels (Canadian Paediatric Society, 2020). Since children, in their early years, generally depend on their families for their wellbeing and development in all areas of life, the family has, therefore, become an important unit of study and analysis in order to adequately assess and meet the developmental needs of children with multiple disabilities.

Thus, with reference to the investigated families and societies reported in this study, the backdrop issues underline family social environment and the important role it plays in enhancing daily routine wellbeing lifestyle and development of their children diagnosed with multiple disabilities. Generally, family structure and function, as underpinned in the Family System Theory and the General System Theory (Bertalanffy, 1968), reveal that an individual can only be understood within the context of his or her family circle or milieu in which he/she is supported to develop adequately. However, the characteristics, structural organization and functioning of the elements in a family interplay with the given socio-cultural, political and economic conditions of their society in a given space and time. Hence, this study focused on family empowerment (Dunst, Trivets, & Deal, 1988) comparatively examined families with such categories of children in the Cameroonian (African) and those of the Swedish (European) societies.

2. Societies and Backgrounds (Sweden and Cameroon)

Both Sweden and Cameroon attempt to apply this paradigm shift approach of integrated and multidisciplinary services in a quasi- identical manner. In Sweden, like in most high income countries, early childhood intervention program, that is aimed to match the special needs of child and family, takes into consideration many factors and it is oriented towards interdisciplinary approach. Besides being child centred, the intervention is also family oriented and community-based (Granlund & Björck-Åkesson, 1996; Simeonsson, 2000 cited by Carlhed, 2003; Carlhed, Björck-Åkesson & Granlund, (2003) and influenced by factors of the social environment. Compared with Sweden, Cameroon, like most medium/low income developing countries, also avails of some of these key intervention components. However, the logistics, resources and strategy available for families' daily adaptation to the developmental needs of their children with multiple disabilities widely differ between both societies due to numerous reasons that this work attempts to explore and explicate in its findings in subsequent sections.

2.1 Sweden

Sweden is a Scandinavian country, situated in North of Europe. It is a high income country with a total land area of 410,335 sq. km and a population of 10,246,901 inhabitants (Statistics Sweden, 2019). In this country much value is attached to wellbeing and development during childhood because it is considered not only as preparation for adulthood and investment for the future but also as an important period in life. This support approach is a common practice in the welfare states of Nordic countries (Tossebro, Gustavsson and Dyrendahl, 1996). During early childhood, there are two natural environments, namely the family and care/preschool contexts that are supportive to child development. As a matter of fact, the Swedish child care service system has two aims: to help parents combine parenthood and studies or employment; and to support and encourage children's development and learning in conditions favourable to children's wellbeing (Swedish National Agency for Education, 2004b cited by Björck-Åkesson and Granlund, 2003). In 1996, the responsibility for public child care was transferred to the Ministry of Education. At the local government level, municipalities have an obligation to provide preschool activities for children whose parents work or study, or for children in need of such activities (Swedish National agency for Education, 2004 cited by Björck-Åkesson and Grandlund, 2003).

Thus, in order to fulfil its mission, the state as the sole provider of such services has promulgated a series of national laws and policies within the medical, social and educational domains to support children including those with disabilities and their families. These policies include: The Social Welfare Service Act (SoL), the Health and Medical Services Act (HSL), the Support and Service for Persons with certain Functional Impairments (LSS), the National Insurance Act and the Education Act (Handikappforum Göteborg, 2004). In Sweden, various support services offered to families with children in need of special support within each of these areas are available at regional, county and municipal levels. In a nutshell, according to Ratzka (2003), the Swedish social policy is the vision of the "folkhem", (literally translated "the people's home"), the view of the state as a close community, similar to the family, where all members in solidarity support each other.

2.2 Cameroon

Cameroon is situated between West and Central Africa. It is a medium income country with a land area of 475,440 sq. km and a population of 25,640,965 inhabitants (World Facts Book, 2018). In Cameroon, services related to children and families' welfare are quasi-liberal and conservative in nature. These services are run by both public and private (lay and missionary) bodies. According to state policies, the public sector manages more than half of the total available services as evident in the following domains: the Ministry of Social Affairs (Sub Department for the Wellbeing of Families and Children) by Act No.83/013 revised in 2010 on the protection of disabled persons; the Ministry of Public Health (Sub Department of Family Health) and the Social Security System (Epede, 2006; Cameroon Report to Treaty Bodies-Committee on the Rights of the Child, UNHCR, 2001; MINAS, 1977, 1983, 1990, 2005 and 2010). Public sector services in this area are offered at regional, divisional, sub divisional and district levels. The private sector services are delivered by the national and international Non-Governmental Organisations (NGOs), private lay and missionary bodies.

Thus, in Cameroon, different bodies are implicated in services available to children and family in need of special support. The state has made provisions for human investment from early childhood by creating many basic educational establishments in all localities. Nursery and elementary schools are not completely free because some amount is levied on pupils as registration fee and parents themselves have to meet the basic needs of their children. There is a flexibility of choice by parents either to give their children a start in low charged state maintained (government) schools or payable private ones. Generally, more than 65% of Cameroonian families are ineligible to state social benefits (family allowance) given only to children of state employees or employees of a contributing private organisation. Since the social security system is not well developed to meet the basic needs of the vulnerable (children and low income families, elderly, disabled, orphans, unemployed among others), many disabled persons are not socially integrated into family, school, community and working life. Although there are many national legal and policy documents that clearly outline provisions of such services to the needy or vulnerable citizens. However, at the level of enforcement, the state doesn't provide logistics and financial resources to meet such special supports to all the vulnerable except the few qualified for family allowance. As a matter of fact, some pre-natal primary health care (vaccinations, clinical services and subsidized drug prizes) and social welfare services (family planning and counselling) are either free or delivered with a low consultation cost for individual families. The indispensable role of international development agencies like UNESCO, WHO, UNICEF, UNDP, ILO and NGOs is noteworthy in supporting service delivery through community-based local private organisations and the state.

For disabled children with physical, mental and sensory impairments, the state of Cameroon has put in place legal and policy provisions to enhance their integration into the low cost school system. Unfortunately, no provision has been made for financial support for these children and their families in response to basic needs except those with severe and complex disabilities who benefit from school fee exemption. In addition, the application formalities are complex and lengthy. Consequently, it is the primary burden of each family to bear the bulk of or all the needs of their child with disability. This situation is aggravated by some ethno-cultural beliefs and practices with negative attitudes towards the disabled that influence family daily lifestyle and routine in the accommodation of disabled children. This has given room to some conflicts among other issues in Cameroon which are typically African (Gluckman, 1973). To remedy the situation, some voluntary national and international NGOs provide part of such special supports to families in desperate need especially those in poverty stricken communities and disadvantaged backgrounds. Limited aids provided by these benevolent private bodies to such families usually include: some finances (raw cash), material (housing and school needs), medical (payment of a percentage of hospital bills, subsidies in prices of drugs bought in pro-pharmacies); psychological support (counselling services against emotional disturbance and difficulties), Educational/social support to parents (resource information and other social welfare services) (Ndame, 2015). One of the crucial problems in the Cameroon's system is that many families are unaware of the availability of such support services while others deliberately neglect them due to the lengthy, complicated and bureaucratic procedures required to obtain support approval and service delivery by the state through its Ministry of Social Affairs' Regional, Divisional and Sub divisional Delegations.

Thus, Sweden and Cameroon have different approaches to child and family health and social welfare services, especially with regards to children and families in need of special support. In Sweden, while the state assumes the entire responsibility of all support services to children and their families, in Cameroon, the state shares the responsibility with parents and other private bodies to offer payable services to only few among the many families and children in need of special support.

2.3 Literature review

The reviewed literature on the investigated research topic and its objectives indicate that diverse assessment and intervention studies have been carried out globally on family adaptation to the developmental needs (health, educational, social care and daily life skills) of their children with co-occurring or multiple disabilities Such health conditions impinge on their day to day wellbeing, functionality and progress in life, that is, they experience developmental delay as compared to other children of their age. However, unlike each of the reviewed previous empirical studies that focused only on some investigated families in single societies, the present study is unique because it is focused on comparing two national family systems (Swedish and Cameroonian). It investigated the extent to which family environmental cultural practices (family eco-culture) influence family organisation, functioning and exploitation of the available resources to support their children with multiple disabilities in their developmental processes. Thus, it strived to elicit commonalities and distinctiveness in both systems in order to discover what is beneficial to the target population of both societies through improvement of health care and social support services to families and their children with multiple disabilities.

2.4 Objectives of study

- To examine the extent to which family economic, political and socio-cultural conditions relate to parental adaptation to everyday functioning of their child with multiple disabilities;
- To enquire the extent to which parental perception of disability influence their support strategies to enhance child development;
- To investigate what extent family organisational structure and functioning affect the use of the available social network resources for child development.

2.5 Research questions

1) To what extent do family economic, political and socio-cultural conditions relate to parental adaptation to everyday functioning of their child with multiple disabilities?
2) To what extent does parental perception of disability influence their support strategies to enhance child development?

3) To what extent do family organisational structure and functioning affect the use of the available social network resources for child development?

3. Research design, population and sampling techniques

A mixed method research design (Amin, 2003; Creswell, 2013) was used with quantitative and qualitative data collected and analysed before being comparatively and contrastively, juxtaposed, interpreted and discussed.

3.1 Population and settings

The target families and their children in this project came from a variety of backgrounds. In Cameroon, families are resident in Limbe, a coastal town, Buea, the South West Regional Capital and their environs. The parents include peasants' farmers, petty traders, unskilled workers that earn low family income while others are skilled middle-class state employed professionals like teachers and treasurers, with medium/high family income. Since most of them live in urban/semi-urban areas, life seems to be very demanding, as evident from their responses to interviews and questionnaires. Their children, assigned anonymous names for ethical purpose of confidentiality, have a variety of multiple disabilities as presented in table 1. Similarly, among the Swedish families resident in Västerås-Capital of the Västmanlands Region and its vicinity, some parents are from high while others from middle and low income backgrounds. Their children also have similar multiple disability problems. While some of these families consider the situation normal and under control, others consider it difficult and express their dissatisfaction with the services offered coupled with the difficult city life.

Table 1: Characteristics of Children with Multiple Disabilities and the demographic information of the selected families in Cameroon and Sweden

Child Characteristics: Nature of disability	**Family Background: Cameroon (F1-5)**	**Child Characteristics: Nature of disability**	**Family Background: Sweden (S1-5)**
1. Abraham Male-3 years Language/hearing impairment	Mother: Farmer Father: Seasonal worker Low income family	**1. Anders** Male, 6 years, Hearing Impairment/ communication problems	Mother: Teacher Father: Teacher High income family
2. Bertrand Male, 5 years Behaviour/Speech impairment	Mother: Teaching Father: Teaching High income family	**2. Lisa** Female 4 years, Deaf Blindness/ Speech impairment	Mother: personal assistant Father: computer consultant High income family
3. Caroline Female, 6 years, Cognition/Language problems	Mother: Petty Trader Father: Security Guard Low income family	**3. Jens** Male 1.5 years, Hearing/ Language problems	Mother: Nurse Father: Housekeeper Low income Family
4. Donald Male, 4 Years, Deafness/speech and	Mother: Secretary Father: Public Treasurer Middle income family	**4. Maria** Female, 2 Years, Deafness/ Social interaction	Mother: Administrative assistant Father: Company manager

language disorders			High income family
5. Elizabeth Female, 3 Years, Blindness/ language problems	Mother: Unskilled labourer Father: Unskilled Labourer Low income family	**5. Gunilla** Female, 5 Years, Speech/ hearing impairment	Mother: Personal assistant Father: Factory employee Low income Family

3.2 Sampling techniques

The study purposively sampled 20 parents from 10 families, that is, 5 families in Cameroon (F1-5) and 5 families in Sweden (S1-5) with their children age range 1-6 years, each with a medically established case of multiple developmental disabilities in diverse areas of functionalities as presented in table 1. The sampling population in Cameroon was recruited with the help of some colleagues at the University of Buea, through the state local social welfare services and some local private support agencies. In Sweden, originally there were difficulties. Due to my limited Swedish language skills, communication was done in English after having selected bilingual (Swedish/English speaking) parents for the study. These arrangements were possible to me, as a guest researcher, due to the collaboration with some senior colleagues of the University of Marladalen in Vasteras and the state social services in the local community.

3.3 Instrument validation and administration

Two instruments used in data collection were Ecoculture Family Interviews (EFI) /questionnaires and Social Network Interviews (SNI)/questionnaires.

The Ecocultural Family Interview (EFI) Manual (Bernheimer, Gallimore,, & Weisner, 1990) and the "family story" (Bruner, 1989) interview/questionnaire guides were structured in 10 domains or dimensions namely- 1-Family Subsistence, 2-Services (social support), 3-School, 4 Childcare, 5 Domestic workload, 6-Family Connectedness, 7-Disabled network, 8-Non-disability network, 9-Religious (spiritual /beliefs) help, 10 Professional help (multiagency health, social and psychological services). All these domains or dimensions of support for wellbeing are designed to assess family adaptability to child disability and child's developmental process. This instrument has a rating scale of 0-2 (low), 3-5 (middle/medium) and 6-8 (high), as found in the Ecocultural Family Interview CODEBOOK frame and scale (Gallimore, Weisner, Bernheimer & Nihiria,1997; Gallimore, Weisner, Bernheimer, Gutherie, & Nihiria, 1995).

The second instrument was the social network interviews (SNI)/ questionnaire guides (Weisner, 1984; Gallimore, Weisner, Kaufman & Bernheimer, 1989**;** Blackstone & Berg, 2002) with open-ended items. They were designed in conformity with the Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners. These instruments were administered to families in two sequences; first, on behalf of the child then for each family itself. This measuring instrument has two main parts. The first part consists of mapping out five Circles of Communication Partners (CCP) paradigm namely: first circle (family members), second circle (friends), third circle (neighbours and acquaintances), fourth circle (persons or support workers paid to interact with individuals or families in need of special support) and the firth circle (universe of unfamiliar partners). The second part consists of identifying five groups of key Communication Partners to the child and the family which include: "primary" partners (P), the most "skilled" partners (S), partners the person spends most of the "time" with (T), person's "favourite" partners (F), partner most willing to "learn" new skills (L) as found on the interview guide.

Both instruments were already well established and used by experts in previous studies in the United States. Thus, they were culturally validated through modification of certain sections, after peer review and approval, to suit the contexts of the families and societies under investigation. The procedure of data collection took four months and the instruments were administered to respondents through self-delivery techniques by the researcher during the appointed time most convenient to each them, in their respective homes, work places and quiet corners closer to their work places. The tape recording of interviews and, distribution and collection of questionnaires lasted between 30-45 minutes each.

3.4 Data analysis

Qualitative data from interviews were transcribed and coded then analysed using the content analyses approach of Taylor and Rener (2003). The qualitative data are later on juxtaposed with quantitative data in the narrative under data interpretation and answers to research questions.

Quantitative data were collected through questionnaires and analysed with the help of statistical package for social sciences (SPSS) (Nana, 2012). There were two set of questionnaires administered to parents: firstly, those designed to gather the demographic information of respondents and secondly, those derived from the eco-cultural family interview for multiple disabilities (EFI-MD) to assess or measure to what extent the various support dimensions affect family adaptability to the developmental needs of their children with disabilities as illustrated in table 2. For the EFI instrument, three indices from the respondents' questionnaires were within acceptable reliability which include cultural sensitivity (alpha value = 0.76), applicability (alpha value = 0.87), framework (alpha value = 0.73). The reliability of the SNI questionnaires for families and children's partners of communication were verified through the Cronbach alpha values of 0.76 . Table 2 reveals the detail of the Cronbach alpha values of the various support dimensions explored in this study which were found satisfactory.

Table 2: Cronbach explanation, item grouping and alpha value of Ecocultural Family Interviews/questionnaires of Multiple Disabilities (EFI-MD) Dimensions as quantitative data

Dimension	Item	No. of items	Alpha
1. Subsistence (Work)	- level and type of work done to earn a living - level of job benefit provision - level of coverage for family health care - level of coverage for child's services - level of jobs changed because of your child - current economic situation	6	0.75

2. Services (Social support to your child)	- level of any social service - level of difficulty to find them - level of satisfaction or dissatisfaction with the social support service(s) provided - other services that you would like to get for your child	4	0.65
3. School (involvement in child school life)	- time spent at child's school and classroom - time spent on school work at home - level of father's involvement in his/her studies	3	0.64
4. Child Care	- level of arrangement for child care - level of difficulties encountered in arranging for child care - level of father's involvement in child care - type of child care offered and frequency of father's service - level of sibling or someone else's involvement in child care - level of child inclusion in family outings and activities - level of family difficulties in handling child care - level of helping the child cope on his/her own - level of child's supervision needed indoors - level of child's supervision needed in the neighbourhood - level of special changes or environmental adaptation required in home or yard to meet the child's needs	11	0.72
5. Housework	- level of house work done - level of most committed helper - level and frequency of father's involvement in house work - level of involvement and types of external assistance provided in house work	4	0.72
6. Family Connectedness	- level of daily routine activities within the family - any elderly/younger sibling(s) and attitude towards the child with multiple disabilities - level of any differential treatment to the child - level of family child care plan and responsibilities now and in future - amount of time you all spend together / any difference in schedule - level of agreement on house work and child care responsibility - level of child care influence on the marriage/ relationship with your spouse - level of feelings that the task of raising a child with disabilities is opportunity / challenge - level of feelings that the task is more of a burden and hardship	10	0.85
7. Involvement of child with disability networks	- level of things child does together with friends with disabilities	3	0.68

	- level of parental effort/ planning to facilitate child's social interactions - level of child's involvement in recreational activities for all children with disabilities?		
8. Involvement of child with non- disability networks	- level of things child does together with school/neighbourhood friends without disabilities - level of child's involvement in recreational activities for all children - level of concerns about the child's relationship with other children	3	0.61
9. Formal and instrumental religious/ spiritual beliefs/ helps	- level of your involvement in church or temple or mosque activities - level of ways you practice your religion - level of support your religious group provides to your child with disabilities. - level of instrumental help your religion or spirituality has contributed in enabling you to raise your child with disabilities.	4	0.85
10. Professional help to family (multi-agency services)	- level of health/psychological/social support - level of parental exposure to resources - level of parental training/workshops/conferences - level of parental involvement in social networks that help in supporting child's development	4	0.65
Total		51	

3.4 Demographic information of respondents

Data collected on the demographic information of the 20 respondents was used in establishing the EFI-MD Codebook for the 10 families and the clinical population of their 10 children with multiple health conditions. Parental age range indicate that 2 (10%) of the parents are below 25 years; 5 (25%) are between 25-35; 10 (50 %) are between 36-45 and 3 (15%) are 46 years and above. Parental education level suggest that 4 (20 %) parents have First School Certificate (7 years and above of schooling); 4 (20%) parents have secondary school certificate (12 years and above of schooling); 6(30%) parents have high school certificate (14 years and above of schooling); 4(20%) parents have Bachelor degree certificate (17 years and above of schooling) and 2 (10 %) parents have Master degree certificate (19 years and above of schooling).Their annual income levels reveal that 10 (50%) parents have low income; 6 (30%) have medium income while 4 (20 %) have high income. Generally, these family background factors of parental age, education level and income level are useful indices in analysing and interpreting data on each of the families' ability to produce and mobilise adequate resources that can help them adapt to their child's multiple health conditions and support the process of their development.

4. Data interpretation and findings

All the 20 parents of the 10 families participated actively in the study. Besides their recorded voices in the interviews and filling of questionnaires, parents' return rate of questionnaires was 100%. This suggests the extent to which they were determined to contribute in this disability and health inclusion study whose outcome would help them in enhancing their heavy daily routine support task. Following the demographic information presented above, the narrative is based on the 10 dimensions that explore strategies used by parents in adapting to the developmental process of their children with complex needs. In order to fulfil their parental roles in sustaining the wellbeing and growth of their children with health conditions, they strategize the day to day tasks through adequate use of the available time, human, material and financial resources.

In this comparative study, interpretation of data is explored through group commonalities and distinctiveness emerging from the analysed data of family questionnaire and interview responses which are juxtaposed in the narrative or answers to the research questions.

4.1 Answers to research questions

Research question 1: To what extent do family economic, political and socio-cultural conditions relate to parental adaptation to everyday functioning of their child with multiple disabilities?

Each of the 10 domains or dimensions of support is explored and interpreted within the comparative perspective.

4.2 Subsistence dimension

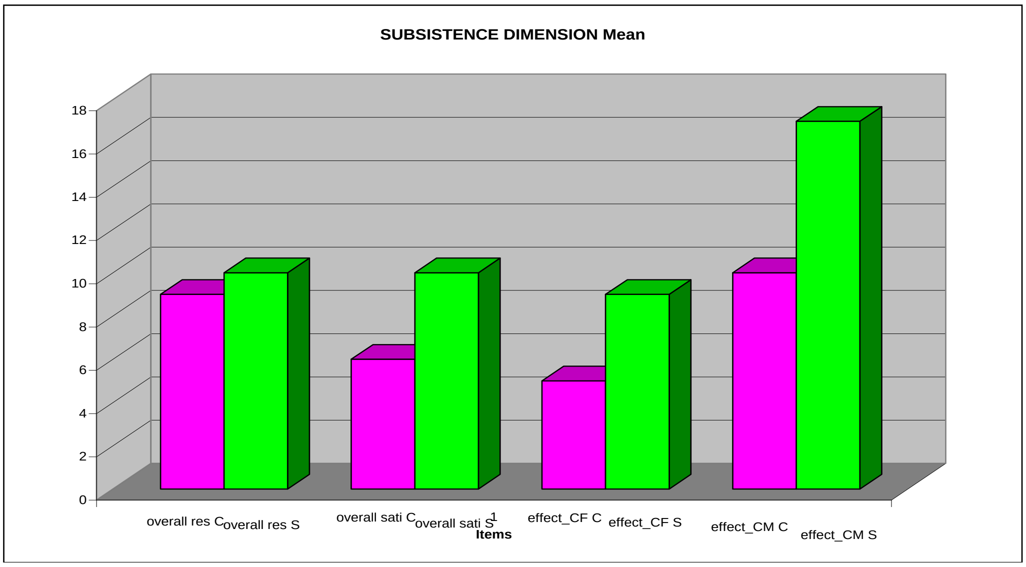

Chart 1: Mean in Subsistence (level of income) between Cameroon (pink) and Swedish (green) Families

Chart 1 of the analysed data shows the mean in subsistence or income dimension between Swedish and Cameroonian families. All parents in the sampled family population are engaged in diversified economic activities and varied levels of family income jobs. Because of the bulk of them (60-70%) have low or medium income jobs, they do not have enough to sustain the family and extra coverage to meet family special needs. Consequently, further support is required to meet the needs of their children with disabilities. According to a family in Sweden, *" In our country, each local community social service supports all families and even more for children with special needs"*(S2). While all families in Sweden have income to meet their basic needs because even the poor ones are supported by the state and many also have additional fund for extra-needs, those in Cameroon fend for themselves (column 1). Columns 2 shows dissatisfaction by most families but more by Cameroon families for the unreliable services they receive. As revealed by a family in Cameroon, *"I have heard of support here, but I doubt whether there are any children with disabilities in this country supported by the government social services. To the best of my knowledge, only my family members, sometimes friends and religious body support us with our child with disability"* (F3). Consequently, among the latter group, features those with low and medium income and majority hardly have back-up fund to cover extra-cost. In terms of the effects of children's condition on parent work arrangements, (Columns 3 and 4) most Swedish families (75-85%) are allocated some time to care for their disabled children while still receiving support from the state but they have to work in close collaboration and negotiation with their employers. In Cameroon, (45-60%) parents have to spend much time outside looking for fund to maintain their family and the disabled child. Since most of them have low paid jobs or are self-employed, they have a greater flexibility in their time schedule than their Swedish counterparts. Thus, Swedish parents, due to state support, have more advantage over their Cameroonian counterparts in terms of subsistence dimension.

4.3 Service Dimension

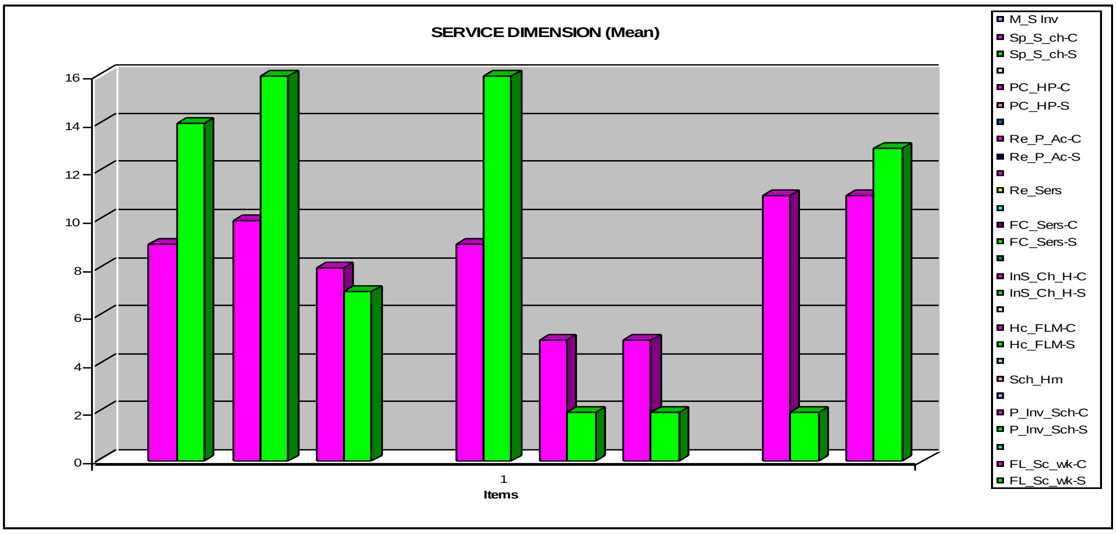

Chart 2: Mean of Service Dimension between Cameroonian and Swedish Families

The analysed data reveal that despite the differences in the quality and quantity of man power, services are available in both societies. Nevertheless, while in Sweden, all health, educational and social welfare services are covered by the government, in Cameroon, each family takes individual care for such services to its members because the state subsidies are limited to only few families. These are evident in the columns 1, 2, 3 and 4 of chart 2 which show how, due to the state support, (85-95%) Swedish families are able to organise child and family services and interact with professionals to meet their needs whereas their Cameroonian counterparts, only (25-30%) have limited support opportunities from few private agencies. However, some Cameroon families, following their socio-economic status, are on the same scale or almost better than their Swedish counterparts. Considering their hard working efforts, plus the help of close to 70% of subsidized free services offered by some private bodies (NGOs and some religious foundations) to few low/medium income families, they also rise to a better level in terms of child school/home care services (bars 5, 6 and 7). This looks favourable with higher recoding for some Cameroonian families (75-85%) in contrast with their unemployed Swedish counterparts (65-70) who maintain the lead throughout the whole chart. As a father in a Cameroonian family unveils, *"Where our extended family members cannot help, we are always looking for a private support agency to help our child with disability"* (F3).

4.4 Political, socio-cultural and religious dimensions

As evident from the analysed data, these three dimensions do not only affect but also influence the way families are organised and function in relation to their adaptability to their children with disability health condition.

Families (80%) from both societies explain that their sociocultural beliefs, attitudes and practices towards the disabled affects the way they adapt to their children's health condition and influence the children's developmental process. In Sweden, all families (100%) acknowledge the existence of the national social welfare and health policies that regulate support services as well as the multi-agency services that educate, train and support parents on disability awareness, human rights and advocacy issues. Thus, disability is perceived by families (100%) as a normal and manageable health condition. In contrast to Cameroonian families, despite the existence of national social and health policies, since most of such families (75%) are neither aware nor supported in any form, only few families (25%) have similar perception of the existence of such policies. Thus, majority still perceive disability health condition superstitiously. This in turn, affects the issue of support service delivery for family adaptability to enhance the wellbeing and development of such category of children.

Data from the bulk of Cameroonian families (80%) on ethnicity dimension reveal that due to lack of adequate public resources to imposed harmonised intervention services, the liberal nature of the system and the multicultural practices in the country, families are exposed to different cultures, beliefs, norms and values that shape their daily goals and actions in the process of adaptation to their children's developmental disabilities. To some, the gods must be appeased to normalise the child's health condition. To others, the child will outgrow the condition through intellectual knowledge acquisition, socialisation and social interaction skills. By contrast, in Sweden, families (95%) focus their daily goals on the child's linguistic, intellectual and social incompetence to know his/her deficiency and what type of intervention service is required to remedy, normalize or adapt to the child's situation.

Analysed data on the dimension of religious beliefs and help, reveal issues of distinctiveness between families of the two societies. In Cameroon, families (75%) reveal that because of their involvement in religious (churches, mosques or traditional worship grounds) activities and local community activities, both religious foundations and private secular bodies (NGOs) take the lead in supporting them with their child with disabilities. In contrast to the Swedish families (80%) acknowledge their reliance on the state for support with their vulnerable children. Since very few Swedish families are religious adherents, religious support and help to them and their children with disabilities are limited and insignificant.

Research question 2: To what extent do parental perception of disability influence their support strategies to enhance child development?

4.5 Home Dimension

Data analysed under this dimension suggests that in Cameroon, most children with multiple disabilities are considered the vulnerable who should be overprotected by parents for fear of bullying peers with provocative and violent behaviours towards them and the general atmosphere of social stigma by some neighbours or members of the community. Consequently, some disabled children are kept indoors, except those who attend schools, *"where they interact only with their siblings, inmates, kinsmen or friendly neighbours"* (F5) as disclosed by a mother of family 5 in Cameroon that embarks on such practices. By contrast, in Sweden, parents protect their disabled children mostly by *"closely supervising them during their interactions with peers* (disabled and non-disabled alike) *in the neighbourhood playgrounds"* (S3) as explained by a mother of the Swedish family number 3. Thus, in both societies, parents are interested in the security and protection of their children with multiple disabilities. Consequently, most of them generally modify their accommodation or change environment, mobilise resources to support them in school homework and modify their daily routine activities especially leisure and working periods for the interest of their vulnerable child at home.

4.6 Child Care/ Domestic workload

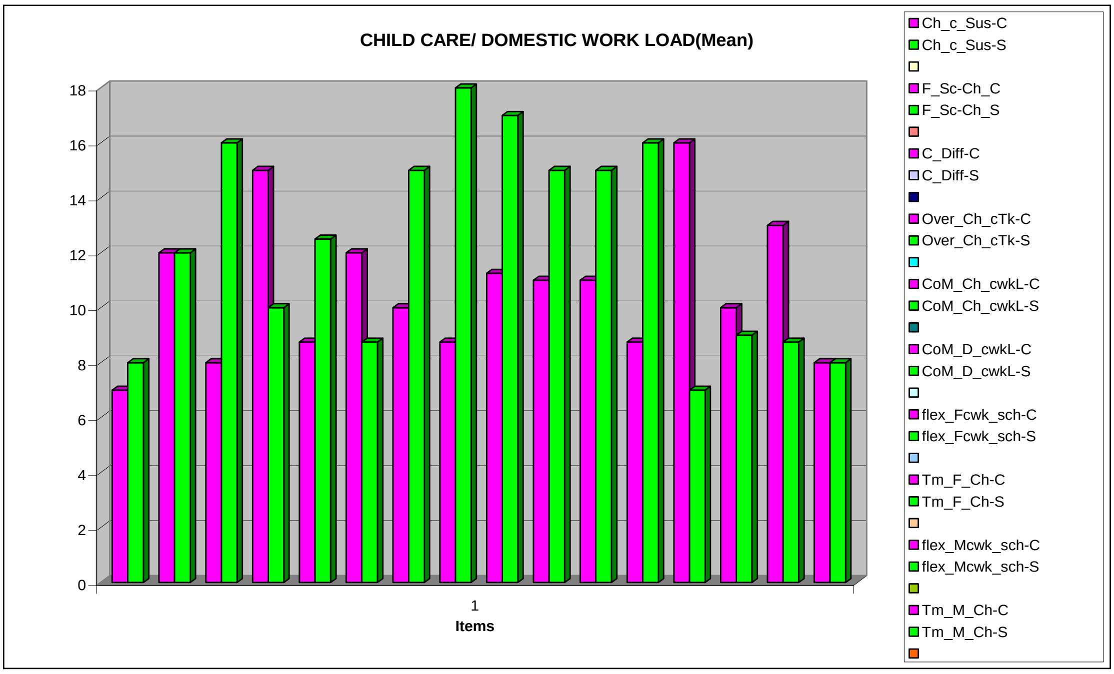

Chart 3: Mean of Child Care/Domestic Workload between
Cameroonians and Swedish Families

Of the 16 bars that constitute the chart of the analysed data above, Swedish families take the lead in bars (items 1, 3, 5, 7, 8, 9, 10, and 11) (65-95%) which can be summed up as heavy involvement in organisation of child and domestic care especially regarding personal, sibling and other family members involvement in day to day care of the child at home. It also includes modification of home environment, contact with professionals, and interaction with the community care resource providers to ensure that everything works well with the family and child in need of special care. By contrast, Cameroon families which take a lead in bars (4, 6, 13, 11, and 15) (55-75%) explain how internal and external family members organise themselves as a synergic unit to face the challenge of child care/domestic workload confronting one member with special needs. Because they do not rely solely on external forces, they work hard with mutual understanding and so they take a lead in this section.

4.7 Family connectedness

In this aspect of family adaptation dimension, data unveil that both societies have quasi-identical patterns of practices. Most of these family members (85-90%) have a clearly defined daily routine role and responsibility to enhance the wellbeing and progress of the entire family. In addition, they have a mutual agreement to work collaboratively in enhancing the disabled child's positive developmental process and to cater for the siblings. Hence, the aim to achieve a common goal becomes the source of close harmony, unity, love and smooth functioning of these families. In this context, mothers receive much support from family relations in childcare and domestic work. In Cameroon, the mother of Family 1 reveals that *"since our families are so large, besides all the siblings, extended members like grandparents, uncles, aunts and even neighbours are all engaged in our child's support and home minding activities"* (F1). Contrary to this strategy, the Swedish families rely more on professionals and pets and less on relations, since their families are relatively smaller consisting of only father, mother and children. Consequently, parents in Sweden have to constantly contact professionals and adjust their time schedule of work and other activities to meet the child's needs. However, in domestic work, Swedish fathers (95%) work in close collaboration with mothers whereas in Cameroon, it is mostly done by all mothers (100%) and other female family members like sisters, grandmothers and aunts. All these family members understand that it is their responsibility rather than just a burden to be shared among all family members to enhance the development of their child with special needs. However, some family members (25-30%) in both societies have mixed feelings on the idea of raising a child with disabilities. This may be as a result of disharmony between parents in their marriage/relationship or in the case of parents who suffer from indecision. Generally, this dimension is indispensable in family adaptability to the disabilities of their child.

4.8 Disability and non-disability networks

Data analysed under these dimensions suggest different aspects of child socialisation for development. In Cameroon, the disability network reveals that three of the families (66.6%) get their disabled children rarely involved in the disability network. As a matter of fact, let alone, most members of these families would not openly get their disabled children exposed for fear of social stigma. With the encouragement and support of some NGOs and philanthropic bodies, most parents send their children to disability organisations and activities. Two of the five families (33.4%) with children with mild to moderate developmental disabilities decline from such projects because they still have expectations that the impairment will disappear in a long run as the child acquires skills in his interaction with non-disabled members of the community. In Sweden, parents (65%) naturally involve their children in disability organisations and activities to create more opportunities to their positive development and social integration. Others (25%) refrain from this act, believing that the child's natural interaction with the general community reinforced by rehabilitation services including daily life skills acquisition can solve the problem of developmental delay. Generally, most families (80%) believe that the social environment namely school and neighbourhood are insecure so they often supervise their children especially those with severe to profound disabilities while in these settings.

Data analysed further suggest that most parents (65%) think that families have a common goal to involve their children into a non-disabled social network as a means to integrate them functionally into everyday community life. There is a difference in approach for those who don't share this idea. Cameroonian families displayed mixed feelings, those (45%) who presume that the child's developmental delay may disappear with time and those (55%) who presume that the multiple disabilities is a permanent and helpless health condition. Such a view influences the way they plan for the child's socialisation and recreational activities and their daily life skills training on how to relate with peers and adults. Their Swedish counterparts (95%) generally presume that through social interaction with non-disabled peers and clinical interventions, the disability health condition will be overcome. However, because of social stigma, they are being over protected in the Cameroonian contexts by parents (80%) who do not give room for any social interaction or limit the types of persons like siblings or relations to socially interact with such type of children. In the Swedish context, respondents (75%) reveal that parents may supervise and authorise their interactions on playgrounds and community social activities if they have mild and moderate disabilities, In the case of severe to complex disabilities, the parents are cautious except under the supervision of a carer or specialist health care provider.

4.9 Professional help to family (multi-agency services)

Analysed data from families (85-95%) in both societies indicate that they make use of professional support services. The multi-agency team of professionals supporting families include: health practitioners (paediatricians, physiotherapists, speech and language therapists an rehabilitation specialists); psychologists (clinical psychologists, school psychologists, and family counsellors); social workers and special educators (for the hearing, visually, mentally and behaviourally impaired). This team of experts supports families in assessing their needs, then planning and administering intervention services for the families and their children with disabilities. Thus, their services are guided by the Individual Family Service Plan (IFSP) plus any additional individual support plan for the child with severe to multiple disabilities. Depending upon their health condition or disability, some of the children have individual health plan (IHP), individual psychology plan (IPP), individual behaviour plan (IBP) or individual education plan (IEP). Among Cameroonian families, (65%) acknowledge that the term professional refers to both modern clinicians and traditional herbalists. The educated and financially viable families (55%) have access to information and professionals while the less educated (45%) do not have access to information, except with the assistance of community NGOs. In Sweden all families (100%) are privileged to have access to professional services, information and resources which are made available to all by the state. All Families (100%) from both societies benefit from professional services. As a Cameroonian parent reveals, *"besides helping us to mobilise the available community resources, professionals also educate and train us on issues of disability/disability related disease awareness, human rights and advocacy issues"* (F4). Similarly, A Swedish parent discloses that, *"thanks to our state and local professionals who help to get us connected to many associations of parents of children with similar disabilities. We can exchange ideas and share our experiences* (S1). Thus, professionals play a vital role in helping parents to adapt to the disabilities of their children as well as enhancing the children's wellbeing and developmental process.

4.10 Group difference in social networks

Research Question 3: To what extent do family organisational structure and functioning affect the use of the available social network resources for child development?

The analysed family data from both societies reveal that investigated family structure, organisation and interaction relate to two main types of social networks partners and their supportive roles. They include the Circle of Communication Partners (CCP) paradigm and key communication partners for each family and child.

4.11 Social networks of the five Circles of Communication Partners (CCP) Paradigm

Table 3a: Circles of Communication Partners (CCP)
paradigm and Number of partners per Family, Child in Cameroon and Sweden

Family/Child	**1**		**2**		**3**		**4**		**5**	
Cameroon	**F**	**C**	**F**	**C**	**F**	**C**	**F**	**C**	**F**	**C**
Circle 1	13	08	06	05	09	09	07	08	06	04
Circle 2	15	05	09	07	12	11	13	04	04	02
Circle 3	09	05	09	03	11	06	10	04	04	01
Circle 4	06	02	07	03	03	05	09	04	01	01
Circle 5	09	00	07	01	10	00	16	02	04	00
Total	52	20	38	19	45	31	55	22	19	08
Grand Total	309									
Sweden	**F**	**C**	**F**	**C**	**F**	**C**	**F**	**C**	**F**	**C**
Circle 1	13	09	03	03	08	08	04	03	06	05
Circle 2	13	08	13	07	08	07	37	12	04	21
Circle 3	08	05	06	04	11	07	24	27	38	03
Circle 4	48	44	27	21	40	23	70	55	38	20
Circle 5	04	00	05	04	10	09	05	00	1020	40
Total	86	66	54	39	77	54	140	97	1106	89
Grand total	1808									

Note: F= Family; C= Child

Table 3b: Mean of the comparative five circles of Cameroon and Swedish families

Mean	
Sweden	**Cameroon**
6	8
13	13
13	7
39	4
122	7

Circle 1: Life partners (e.g. mother, father, son, daughter, grandmother, grandfather);
Circle 2: Good friends (colleagues, school friends among others);
Circle 3: Neighbours, acquaintances (e.g. neighbours, ex mates);
Circle 4: People paid to interact (e.g. speech therapist, special teacher);
Circle 5: Universe of unfamiliar partners (members of the community)

With regard to the general review of the five Circles of Communication Partners (CCP) Paradigm, this area explains about the daily transactions between both family and non-family members. In this section that focuses on network resources, the analysis on social network partners target two groups of beneficiaries namely: families and children in need of special support in both Cameroon and Sweden. With reference to the collected data from Cameroon and Sweden, analysis of these aspects of family culture attempts to elicit the differences and similarities of family daily social interactions and their usefulness to those in need of special support.

As revealed by table 3a above, in Cameroon, two of the five families number 2 (n=38) and 5(n=19) have limited numbers of CCP due to their willingness to isolate their disabled children for fear of social stigma. Some have few while others have relatively high numbers of CCP because they intend to expose the child to a wider social environment to help them develop positively. In Sweden, all the families have high numbers of CCP with one family number 5(n=1106) extremely high with almost all community members included. As a result, the overall CCP is (n=309) for Cameroon and (n=1808) for Sweden families. This implies that Swedish families make use of more social network partners than their Cameroon counterparts. However, in the mean of (table 3b) above, it is evident that in:

Level 1 (Circle 1) mean score (6-8), Cameroonian families make use of more (life partners) communication partners than Swedish families. This is due to the general fact that in the Cameroonian society, the nucleus family is larger in structure and function than the Swedish. It consists of parents, children, maternal and paternal grandparents and extended kinsmen, all living under the same roof, whereas in Sweden, it consists of only parents and children;

Level 2 (Circle 2) mean score (13-13), Cameroon and Sweden have a tie in terms of number of (good friends) communication partners. With this aspect, each family has the free will to decide how many friends to make. This ranges from colleagues at work or mates to persons offering services in one way or the other to the family;

Level 3 (Circle 3) mean score (13-7) Swedish families score higher than Cameroon families in terms of number of (neighbours and acquaintances) as communication partners. In Sweden, this is probably because the families with special needs in Sweden are more opened and construct beneficiary wider network groups including pets than their Cameroonian counterparts;

Level 4 (Circle 4) (39-4), Swedish families make use of more (persons paid to interact) than their Cameroonian counterparts. The reason is that the Swedish society has a stronger manpower than the Cameroonian society in terms of quality and quantity of personnel as evident in the variety of professionals and inters-agency community services provided to children and families in need of special support.

Level 5 (Circle 5) (122-7), Swedish families still register more for the (universe of unfamiliar partners) communication with members of the community than Cameroonian families. This is partly due to the fact that most Cameroonian families in need of special support hardly expose the disability condition of their child or their special need issues to the public for fear of social stigma.

The study also identifies **five key communication partners** which include- Primary partners (P), Most skilled partners(S), Partners the person spends most time with (T), Person's favourite partner (F), Partners most willing to learn new skills (L).

4.12 Key communication partners for each family and child

Table 4: Total Number of Communication and Key Communication Partners per Family, Child and Grand Total in Cameroon and Sweden

ID	**Family**		**Child**		**Total**
Cameroon	**Number of communication partners**	**Number of key communication partners**	**Number of communication partners**	**Number of key communication partners**	**Per Family/ Child**
1	52	13	20	11	96
2	38	15	19	11	83
3	45	06	31	10	92
4	55	12	22	12	101
5	19	14	08	07	48
Total	209	60	100	51	420
Sweden	**Number of communication partners**	**Number of key communication partners**	**Number of communication partners**	**Number of key communication partners**	**Per Family/ Child**
1	86	15	66	17	187
2	54	09	39	15	117
3	77	10	54	25	166
4	140	11	97	08	256
5	1106	50	89	17	1262
Total	1462	95	345	82	1984
Grand Total					2404

In examining the issue of key communication partners for families and children under study, the analysed data also reveals some aspects of differences and similarities. As displayed in table 4 above of the total number of key communication partners, it is evident that something remarkably general is noteworthy. Within the Cameroonian families, most primary partners (P) and partners willing to learn (L) are usually life partners or members of the nucleus family while the others like most skilled (S), favourite (F) and persons with whom most time is spent (T) are usually friends, classmates or neighbours. For the Swedish families, there is no precise uniform pattern for identifying the key communication partners. In some families, it depends upon who may be available at a given time or friendly to the child and family in need of special interaction support. For others, it depends upon how opened the family is to outsiders and the type of communication intervention programme delivered to the family during the assessment exercise. Thus, even at the time of this study, the role of key communication partners was alternating between parents, siblings, friends, acquaintances and classmates or colleagues.

5. Summary of findings

- Family conditions relating to their adaptation to children's multiple disabilities:
  - sacrificing extra time;
  - rescheduling working hours;
  - Adjusting income, expenditure and plans.
- Family strategies to meet their children's special developmental needs:
  - Parental perception of disability;
  - exploiting community support resources;
  - professional help
- Family organisation to support children with multiple disabilities is affected by:
  - social network resources;
  - linguistic factors.

5.1 Discussion

Research Objective 1: To examine the extent to which family economic, political and socio-cultural conditions relate to parental adaptation to everyday functioning of their child with multiple disabilities.

This objective has been attained since findings indicate that the family economic, political and socio-cultural conditions are related to their adaptability to the developmental needs of their children with multiple disabilities.

Findings of this study reveal that most of the families are low and medium income earners. Such socio-economic status presupposes that much time is spent or rescheduled in work places for extra hours and pay by parents in order to earn sufficient income that sustains the family basic needs and pay for professional support service for their child, especially in the context of Cameroon where there is little or no state support for such categories of families. Such a situation will therefore deprive the parents, especially the father, of the opportunity to support and care for the vulnerable child at home. However, findings unveil that the bulk of parents, except few who still isolate such children in the dark room, make it possible to sacrifice time, adjust their income, expenditure and plan of their daily schedules in response to the child's needs. Where they are so occupied, extended family members may help in caring for the child. In addition, special day care centres and specialist child minder services are also used by parents in both societies during working hours. Through these daily routines lifestyle and rituals, parents are able to effectively relate to the health condition of their children while overcoming daily stress and enhancing communication skills required for the social development of children. This finding is in line with those of Schuck and Bucy (1997) Mactavish and Schleien (2004).

Politically, families of both societies benefit from the health and social policies formulated and laws enacted by their respective state authorities to implement their health, psychological and social support services for families and their vulnerable children. Unfortunately, while these policies are fully implemented in Sweden, they are only partially implemented in Cameroon which gives room to parents to seek extra-support from NGOs and extended family members. The difference is that the human right-based support services offered by the state of Sweden to families are guaranteed and sustainable, whereas the partially humanitarian or charitable support provided by the state and private bodies to families in Cameroon is indefinite and unsustainable. Consequently, many families in the latter society either go for long or throughout their life span relying only on their personal efforts without any external support.

Findings also suggest that the relationship between the families from both societies and their adaptability to their children's daily developmental needs is affected by their socio-cultural conditions. The socio-cultural organisation of family structures and functions affects family adaptability process to the daily support and care of their disabled children. While the small Swedish nucleus families usually rely on themselves in collaboration with the state professionals, the large Cameroonian families rely mostly on extended family members with little or no external professional support from the state or private body (NGO or religious foundations). However, the sharing of child care responsibility and domestic workload varies as Swedish fathers are more committed than most of the Cameroonian fathers who (may be the only family bread winners) presume that such a task is feminine and is usually abandoned to mothers, grandmothers, sisters or female family relatives. However, with recent global advocacy on human rights-driven society, inclusion and disability awareness issues, the structures and functions of family systems are fast changing in most societies including the ones investigated in this study. Similarly, the findings in the studies of Granlund and Wilder (2006) and Granlund and Olsson (1999) suggested the usefulness of broader ecological niches and multidimensional approaches to communication intervention services to families with children with severe disabilities.

Thus, the family economic, political and socio-cultural conditions account in the way parental adaptation relate to everyday functioning and development of their child with multiple disabilities.

Research Objective 2: To enquire the extent to which parental perception of disability influence their support strategies to enhance child development

Findings of the study suggest that families from both societies perceive disability differently. At family level, the socio-cultural perception of, attitudes and practices towards the disabled generally affects the way parents strategize to support their vulnerable children. On the one hand, findings indicate that all families in Sweden and some in Cameroon understand disability as a health condition that can be treated and managed through professional help including multi-agency conventional health, psychological and social intervention services and care. On the other hand, data reveal that some families in Cameroon understand disability superstitiously that requires traditional medical intervention services by herbalists. The attitude of the former group is positive whereas that of the latter group is negative towards the disabled.

This explains the fact that families strive to exploit community support resources be it of human, material and financial nature to enhance their children daily progress. Through professional help, families collaborate with health, psychological, educational and social professionals for assessment, planning and intervention as well as follow-up services for their children with diverse categories of disabilities. The Individual Family Service Plan (IFSP) usually drawn by the multi-agency task force is implemented alongside the child's Individual Health Plan (IHP) and/or Individual Psychology Plan (IPP) and/or Individual Education Plan (IEP) depending upon the child's area(s) of significant disability or special needs. Families usually carry their children to various professionals where they receive different types of support services including speech and language therapy, physical rehabilitation, daily social life skills, applied behavioural analysis among others. Thus, the multi-agency task force has a vital role to play in supporting the children and in helping families to adapt to the developmental needs of their children with multiple disabilities. Through this process, there is family empowerment and self-management in collaboration with multi-agency or community-based rehabilitation services to optimize the child's communication and developmental process. Other previous works with similar findings include the studies of Granlund, Björck-Åkesson & Olsson (1993), Knox, Parmenter, Atkinson and Yazbeck (2000), Björck-Åkesson, Granlund & Carlhed (2003) and Epede (2006). Another similar finding reveals how professional service enables families to develop positive coping and positive adaptation strategies in supporting their children with disabilities in developmental process (Ylvén, Björck-Åkesson and Granlund, 2005) as well as how parents relate to short- and long-term psycho-social consequences of childhood cancer health condition (Tremolada, Bonichini, Weisner, Basso and Pillon (2013). Contrary to these results, the study of Taverna, Tremolada, Bonichini, Basso and Pillon (2016) revealed that parents of children with leukaemia health condition reported their children significantly less adaptive functioning in the domains of communication, Socialization and motor abilities. Consequently, parents also found it difficult to adapt to the health conditions.

These explanations accounts for how parental perception of disability influences their support strategies used to enhance child development.

Research Objective 3: To investigate what extent family organisational structure and functioning affect the use of the available social network resources for child development

Findings unveil that families in both societies are structurally and functionally organised in line with the pattern in their cultural systems. This in turn affects their use of the available social network resources amidst some linguistic factors that facilitate communication, social interaction and socialization skills of children with complex developmental needs.

The analysed data reveal that the typical Swedish (European) family is small since it is made up of merely the nucleus members-father, mother and child (ren) whereas the Cameroonian (African) family is large consisting of the nucleus plus extended members of the children's maternal and paternal relatives, all of whom play a vital role in supporting parents with a child with complex needs. This means that, in the Swedish family system, the choice of the social network resources that can support the disabled child targeting the above skills generally include paid professionals, disabled and non-disabled peers on community playgrounds and schools, parents and family pets. For the Cameroonian families, paid professionals which are sometimes limited in quality and quantity, extended family members and some community members constitute the social network. The social network of the Swedish families is therefore relatively larger.

However, in terms of linguistic variety in social network resources, the children with speech and language difficulties in a multilingual society of Cameroonian families have multiple language (English, French and African language) resources and communication partners, whereas in a monolingual society like Sweden, the children have a single language (Swedish) resource and communication partners. The exposure of children with speech and language impairment to a single language set of communication partners (ranging from professionals to pets in Sweden) and to many language sets of communication partners (ranging from professionals to extended family members in Cameroon) are significant in the children's communication, social interaction and socialization skills development. The families are therefore meticulous, generally supported the professional team, in selecting the available and most appropriate social network resources that can meet the developmental needs of their children with multiple disabilities.

With respect to the development of communicative skills for children with disabilities and their families, this section of the study focused on the setting up of the circle of communication partners and, the interaction between the partners and the children to enhance their development in communication skills. Other previous studies with similar findings are those of Goldbart (1987), Stephenson & Dowrick (2000), Wilder, Axelsson and Granlund (2004).

Thus, the above discussion suggests that family organisational structure and functioning affect the use of the available social network resources for child development.

5.2 Implication for practice

The study may be useful in Cameroon and Sweden for further research and practice in health and social care services and cross culture family-based and community-oriented intervention services. Similarly, it could be used for international social work development projects on families with children experiencing multiple disabilities within the investigated societies or similar ones of the European and African contexts. Although its findings may not be globally generalised, since it involves families in developed and developing societies, the findings could be partly helpful in enhancing exchange programs in intercultural studies, inclusive education and early childhood intervention projects in similar societies.

6. Conclusion

This study assessed, in a comparatively perspective, how 10 families adapt to daily routines of the developmental needs of their children with multiple disabilities in order to enhance their wellbeing and learning. The study sampled (N=20) parents from 10 families in Cameroon (5) and Sweden (5) using the mixed method approach of ecocultural family interviews (EFI)/questionnaires and social network interviews (SNI)/questionnaires to data collection and analysis. Findings reveal aspects of fundamental commonalities in daily adaptation of families to their children's health condition through: sacrificing extra time; rescheduling working hours; adjusting income, expenditure and plans; exploiting the available social support resources to meet the children's special developmental needs. In addition, since families perceive multiple disabilities as a critical health condition, they maximise the scope of support activities in order to facilitate child development. In distinction, Cameroonian families are structurally larger in size since they include extended members than the Swedish which consists of only nucleus members. Functionally, the former is dependent upon and interacts more with extended family members while the latter makes use of outsiders ranging from professionals to pets for child support services. In child functioning and communication skills development, children in the standardized monolingual society of Sweden change key communication partners indiscriminately whereas those in the multilingual society of Cameroon permanently cling to one or few partner(s) influential in enhancing their development. However children exposure to one language (Swedish) set of communication network of partners differs from children exposure to many language (English, French and Cameroonian) sets of communication partners.

In conclusion, the study recommended that parents should be given more professional help and voice in policy making regarding the support of their children with multiple disabilities.

About the Author

Ndame Thomas (EdD) is a professionally trained inclusive education consultant, practitioner, researcher and lecturer. He is holder of the following academic and professional qualifications: BA Bilingual Modern Letters (English/French) and Postgraduate Diploma (DPESS II-ENS) University of Yaoundé I, Cameroon; MA Teaching of French as Second/ Foreign Language (TOFFL), University of Buea, Cameroon; MEd Special Education, University of Marladalen, Sweden; EdD Special Educational Needs, University of Exeter, UK. He is lecturer and researcher in the: Department of Educational Psychology and Special Education at the Faculty of Education, University of Buea, Cameroon; Department of Special Education at the Bamenda University of Science and Technology (BUST) Bamenda, Cameroon. Presently, he is a Research Fellow in Inclusive Education Administration and Leadership, Department of Educational Administration, College of Education, University of Saskatchewan, Canada. As inclusive education consultant and practitioner, he is founder and chief executive officer (CEO) of Multipurpose Support Association Centre (MUPUSUAC) website: www.mupusuac.net, a Buea-based charity organisation. The multi-task force services of the community-based organisation include: School and Community Inclusive Education Projects; Community Health Promotion Outreach for disability and disability-related disease awareness issues, methods of prevention and management; Individual Psychosocial Therapy; Assessment and Intervention (Early Childhood Intervention-ECI and Late Adulthood Intervention-LAI). He has research and practical interests in Disability Studies, Inclusive Education Administration and Leadership, Multi-agency services, Teacher Education; Assessment and Intervention and, Gifted and Talented Education. His national and international training and practical working experiences in Cameroon, Sweden, UK and now Canada have helped in shaping his present professional portfolio. He is also a member of some national and international professional organizations including the International Association of Special Education (IASE), USA and finally a board member of an academic journal, the European Journal of Special Education Research.

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