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Shaping the early care and education of young deaf children in Ghana

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Abstract

Early childhood care and education (ECCE) for deaf^f children is facilitated in economically rich countries by early identification and prompt access to family-centred intervention. For most low-income countries, this starting point cannot be assumed, and context-sensitive models are needed. Interviews with caregivers of deaf children in Ghana highlight the value of understanding the influence of the environment on caregiver-child relationships and supportive interaction as a basis for the development of ECCE.

Keywords; deaf children, deaf education, early childhood education, inclusive education

1 Introduction

Early care and education (ECE) for all children (from birth to school entry) is essential to children's survival, growth, development, and ultimately their ability to contribute as global citizens to a sustainable world. Article 24 of the United Nations Convention on the Rights of Persons with Disabilities states the right of persons with disabilities to education that is inclusive at all levels (2006) and access to quality ECE for all children is a United Nations Sustainable Development sub-goal (SDG 4.2). The achievement of this goal throughout the world, and especially in low- and middle-income countries (LMICs), is precarious given the global resource inequities and imbalanced access to knowledge-networks (Bizzego et al., 2020).

Currently, the most vulnerable of the world's children - those who are disabled, living in poverty and disadvantaged - are excluded from ECE thereby exacerbating the inequities of marginalization and discrimination. This includes deaf children for whom ECE provides a lifeline to language and communication support, contact with other deaf people and sign languages, and access to hearing technologies (Yoshinago-Itano, 2003, 2014).

According to World Health Organisation (2020) statistics, there are 466 million people, that is 5% of the world's population, who have a disabling hearing lossⁱⁱ that inhibits the ability to communicate with others (Olusanya et al., 2014). Most live in LMICs with limited access to appropriate hearing health services (WHO, 2020). Around 34 million are children for whom being deaf in the critical stages of early development compromises the acquisition of a language (sign or spoken) that is shared by family, community, and peers (Moeller et al., 2013). There is a pressing need for the development of ECE for deaf children and their caregivers in LMICs, but current models of good practice are not inclusive of these contexts.

ECE starts with the early detection of hearing loss that ideally takes place within the first four weeks of a child's life. Universal early identification programmes are now well established in most economically rich countries (Desalew et al., 2020, Olusanya & Newton, 2007). These programmes provide an entry point to intervention and subsequent ECE. Current consensus on best practices for ECE for deaf children and their caregivers is based on Euro-Western (USA, Canada, Europe, Australia) perspectives on early childhood and caregiving, and assumes a certain level of financial resource and hearing health infrastructure (Moeller et al., 2013). In the consensus guidelines, models of good practice presuppose the

availability of hearing technologies and trained qualified (deaf and hearing) providers with the requisite skills and knowledge to support child development and family well-being (Yoshinaga-Itano, 2014). In these guidelines, societal stigma around being deaf and other disabilities prevalent in many LMICs is not anticipated (Baffoe, 2013).

For inclusive models of ECCE to be developed, the knowledge base surrounding current approaches needs to be infused with indigenous knowledge and local expertise (Morelli et al., 2018; Nsamenang, 2008). This involves developing understandings of the distal and proximal cultural contexts for ECCE for deaf children including approaches to caregiving and language learning, understandings of childhood deafness, and disability more widely (Kabay, et al., 2017; Singal and Muthukrishna, 2014).

In this paper we investigate the issues involved in the development of contextually sensitive models of ECCE for deaf children and their caregivers in LMICs, focusing specifically on Ghana in sub-Saharan Africa. Through interviews with caregivers about their experience of parenting and early support we examine the cultural and resource dynamics of ECCE and the interconnecting influences on the development of this provision.

2 Critical understandings of ECCE for deaf children

Having a deaf child can be life changing for caregivers who have no previous experience of deafness, limited understanding of the developmental and educational precarities, and who are unfamiliar with the potential of sign language and deaf community networks. For caregivers, there is a lot to learn about language and communication, there are decisions to be made in relation to technologies, support services and education, potentially new financial pressures, and possible changes required to family behaviours and interaction. The culmination of these new caregiving demands is potentially burdensome for parents and the resulting experience of stress can impact on their child's social-emotional development and well-being (Hintermair, 2006, Quittner et al., 2010).

There is international consensus that caregivers of deaf children need information and support that is professional and family oriented (Yoshinaga-Itano, 2003). The timing of this support is recognised as crucial. The Early Hearing Detection and Intervention (EHDI) guidelines recommend that screening, diagnosis, and early intervention are completed by one, three and six months of age, respectively (Yoshinaga-Itano et al., 2020). In the last two

decades, screening instrumentation has become increasingly sophisticated and suitable for newborns. Newborn Hearing Screening (NHS) within the first few days of a child's life has facilitated early detection. Where corresponding follow-up intervention and support is in place, screening is an effective catalyst for ECCE service provision. Most economically rich, and some middle-income contexts now have NHS near or fully in place (at least above 85% coverage). This coverage is closely correlated with average living standards and economic well-being (Neumann et al., 2019). However, the cost implications of systematic NHS and the lack of infrastructure around epidemiological reporting are a central constraint for LMICs (Olusanya et al., 2012).

Current best practice guidelines stipulate that professional support for young deaf children and their caregivers should be a prompt and holistic process that recognizes the strengths and natural skills of the family, and supports development (Moeller et al., 2013). It is expected that this support is delivered by skilled and qualified multi-disciplinary teams that include deaf professionals (Gale et al., 2021), and that the intervention is sensitive and responsive to different family contexts, values, and cultures (Störbeck & Young, 2016). Alongside professional support, it is understood that caregivers benefit emotionally from informal social support from family, community, and friends (Rodrigo et al., 2007; Zaidman-Zaid, 2007).

Crucially, these guidelines stress the importance of parent - child interaction as one of the main predictors of children's language outcomes. The need to evaluate caregivers' interaction skills is thus a major focus of research and a substantial body of work in the Euro-Western literature focuses on the quality of parent - child interaction and how it can be measured (Curtin et al. 2021).

The extent to which these international guidelines are inclusive needs to be critiqued for three reasons. Firstly, the early detection targets presuppose a level of infrastructure and economic resource that cannot be assumed for LMICs. Secondly, intervention approaches do not consider the global diversity of familial and social networks that surround children and families, and the significant role of the collective in early education and care in some societies. (Grech 2009; Singal & Muthukrishna, 2014). And thirdly, the emphasis on children's language outcomes and quality interaction in the home may not fit with different caregiver communication practices, the social dynamics of interaction and local understandings of child

development (Keller et al 2004). For these reasons it is important to understand the full ecology of young deaf children's lives and draw on locally based knowledge and expertise as a basis for ECCE (Kabay et al., 2017).

2.1 The research context

This project takes place in Ghana in sub-Saharan Africa (SSA) that is one of the world's regions with a high prevalence of deafness. In SSA 1.9% of children under five are identified with a disabling hearing loss as compared to 0.4% of children in economically advantaged countries. Major causes of deafness, such as pre, peri and post-natal risk factors and childhood illness, are compounded by poverty and malnutrition. Most cases are preventable or could be treated, if identified early enough (Tucci et al., 2010).

In Ghana there is a developing infrastructure for coordinated education and health services for deaf and other disabled people. Ghana has a developing Ghanaian Sign Language (GhSL) and an active national association of the deaf (GNAD) that campaigns to reduce the social isolation and marginalisation of deaf people (Nyst 2010, Opoku et al., 2020). However, the early support of young deaf children and their caregivers is an unmet need (Oppong & Fobi 2019).

In Ghana, as in most LMICs, the infrastructure around ECCE is not available to caregivers of deaf children. Ghana has no national newborn hearing screening programme and diagnosis of childhood deafness is typically late (20% of children are not identified until after their fifth birthday). Hearing screening mainly takes place at regional centres through behavioural testing after referral. Over 80% of children are identified before their third birthday, but this is still suboptimal compared with the objectives of screening within the first eight weeks of life. There is no established cochlear implant programme at this time; the first cochlear implant took place in Ghana during the drafting of this paper (November 2021). In a country where over one million people have a hearing loss there are currently only 25 licensed audiologists and 320 qualified teachers of the deaf who are currently teaching in the 14 schools for the deaf and two inclusive schools.

There are no early year's programmes for deaf children although some schools and clinics offer pre-school language and communication support to families. However, non-enrolment in pre-school programmes is common and can be as high as 70% where parents fear prejudice and stigmatisation and prefer to shield their deaf children from society rather

than disclose their deafness. Most do not see themselves as legitimate collaborators or advocates for their children's education (Oppong, 2003).

Very little research on ECCE in the context of deaf education has been published in SSA, or in Ghana specifically. There are some descriptions of ECCE for deaf children in LMICs including other SSA contexts, notably Ethiopia, Nigeria, Namibia, Kenya, and Tanzania, as well as India and Sri Lanka, that document late identification and the lack of widely accessible early educational programming (Knooks et al., 2019). The lack of systematic NHS reported in these studies delays intervention and support. The geographical inaccessibility of the available support for many families and the dearth of trained practitioners means young deaf children miss out on ECCE, and parents do not get the professional or peer support that they need in the early days of their deaf child's life.

Empirical studies highlight the challenges of early communication among caregivers and their deaf children and the implications for children's cognitive and social development, well-being, and educational outcomes (Akellot & Bangirana, 2019). Parental stress and anxiety are reported in relation to communication, behaviour and educational support and the influence of negative attitudes towards deaf people on caregivers are recognised. In this research there is a tendency to describe challenges as child- or parent-centred and focus on the development of 'better parents' (through training and intervention) rather than more accessible and appropriate ECCE structures and processes (Wanjiru et al., 2014). Opoku et al (2020) extend this perspective by situating the provision of support services to families of deaf children in a wider discussion of the inclusion of deaf children and their families in Ghanaian society.

The HI HOPES initiative in South Africa is a widely reported model of good practice. This family-centred, home-based intervention encourages all communication options and provides unbiased, informed support to caregivers from deaf and hearing mentors. Improvements in children's language development and a high level of caregiver satisfaction are reported & Pittman, 2008). However, South Africa has an NHS programme and so caregivers can be engaged in the very early of days of identification. More typically, the engagement of caregivers is reported to be problematic. Olusanya & Newton (2007), in their survey of 18 LMICs, found the beliefs and attitudes of the community around the family to be an inhibiting factor in terms of parental acceptance of deafness and uptake of support. In

general, early support was not widely understood or appreciated. These findings underline the need to examine different care and education values and practices at the levels of family, community, and society, and to listen to the lived experiences of caregivers in the shaping of ECCE.

3 The current project

This paper reports on a collaborative research project that investigates ECCE for young deaf children and their caregivers in Ghana. The aim of this project is to develop critical understandings of the social and resource contexts of young deaf children to support the development of ECCE that can be replicated across different urban and rural contexts. As well as contributions to the ECCE knowledge base, the project aims to build sustainable research and development capacity and Africentric ECCE scholarship.

3.1 Methodology

The theoretical framework for this work conceptualises caregiving as part of a sociocultural context where biology and culture are intertwined (Keller et al., 2004). A bioecological framework (Bronfenbrenner & Morris, 2006) is employed to analyse the interconnecting influences on early development, care, and support (Davis et al., 2021). Data gathering involved interviews with 12 caregivers about their experiences of raising a deaf child.

3.2 Recruitment of participants

Participants were recruited from Southern, Middle and Northern sectors of Ghana through approaches to three schools for the deaf and two speech and hearing assessment centres. In total, 12 caregivers came forward to participate including eight mothers, three fathers and one grandmother, all with children between the ages of 5-15 years. Due to late identification and lack of reporting it was not possible to recruit parents of pre-school deaf children. Five of the 12 participants were single parents. This is a small sample, and the intention is not to generalise but to analyse the response of caregivers to identify insights for ECCE development that may be pertinent to wider contexts.

Table 1. Participant overview

Caregivers	N = 12
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Relationship with child	Mother	8
	Father	3
	Grandmother	1
Location	Ashanti region	3
	Central region	4
	Greater Accra region	4
	Eastern region	1
Education	No formal education	1
	Basic level (primary and junior school)	7
	Secondary	1
	Tertiary	3
Employment	Trader	4
	Semi-professional	5
	Professional	3
Age of deaf child	5-10	9
	11-15	4
Sex of deaf child	Male	11 ⁱⁱⁱ
	Female	2

3.3 Interviews with caregivers

We collected brief biographical information about each caregiver including details of their education and employment. We invited them to give details about their children and asked about the community and the relationships around the child and family. Caregivers were asked about their experience of caring for a deaf child focusing on: identification and diagnosis, language and communication, support needs and possibilities, and expectations.

Three of the interviews were conducted in spoken English, six were conducted in the local language (Twi), two were conducted in the local language (Fantse), and one in blended English and Twi. Each interview was audio recorded and transcribed directly into the local language by the local researchers, after which, a transcription in English was prepared. We checked and cross-checked each transcription to ensure conceptually accurate translations

(Temple & Young, 2004). To protect the privacy of the participants and anonymize their responses we refer to them as Caregiver 1-12 and shorten this to C1, C2 throughout the text.

3.4 Analysis strategy

A staged thematic approach was applied to the analysis of the interview data (Braun & Clarke, 2006). To mediate cross-cultural interpretations of the data, the project team worked together to build a coding instrument. All the team members independently reviewed the interview transcripts and then discussed each one to challenge perspectives, add context and zoom closer into the lives of the participants and the cultural context of the data. From the integration of these perspectives a coding handbook was developed. This was used to markup transcripts individually before full team agreement on the assignment of codes to the main themes and the emergence of any new themes and sub-themes. This was an iterative process that involved small group and whole team meetings to review, discuss and contextualise different interpretations of interview extracts.

4 Findings: The experience of caregivers

The main themes that emerge from the analysis of the interview data centre on the caregiver's experience of having a deaf child and the different ways in which they come to terms with their new parenting situation. Central to their concerns are anxieties about language and communication. They reflect on the different opportunities for formal and informal support and articulate their hopes and expectations. Their responses reveal the different ways in which the proximal processes of caregiving are influenced by the wider environment and distal processes.

4.1 Encountering and overcoming difficulty

An initial negative reaction to having a deaf child on the part of the caregiver is a strong theme across the interview data. All 12 of the caregivers describe experiencing difficulties with acceptance, as well as sadness, grief, and guilt. This response was usually linked to their concerns over communication and feelings of shame and guilt.

So, I don't accept that he is deaf and can't hear or talk (...) sometimes I become discouraged and sad for giving birth to a child like this. C4

Caregivers talk about their difficulties in accepting that their child is deaf and their personal feelings of sadness. They describe the experience of being in unfamiliar territory, encountering new decisions and how they make sense of their situation. Of the 12 caregivers that we spoke to, only two had previous experience of deafness in the family.

In different ways, all the caregivers talk about a process of acceptance and of seeing that 'it is not the end of life' (C5). Acceptance for some caregivers is described in philosophical terms as a 'letting go' and shift in perspective.

As time went on, I accepted the fate of the child because I felt it had happened and there was nothing to overturn it so I rather directed my attention to how I could raise him to be useful to the society rather than to think daily about his plight. C8

4.2 Marginalisation

Caregiver feelings of grief, sadness, guilt and shame and their experience of burden is influenced by ways in which other children and adults respond to their deaf child and the experience of stigma in the wider societal context. Limited understanding of what it means to be deaf in rural and urban communities engenders discrimination at a personal and societal level. Seven of the caregivers talk about other adult's behaviours and being singled out as different.

In the community the major problem we have is stigma. Usually when you have a child with disability people look at you in certain way and therefore for your child if you don't take care, the self-confidence will be broken because they point fingers all the time at you and when that happens it becomes a problem. C6

Stigmatization is sometimes exhibited by young people calling deaf children names such as 'mumu'^{iv} and putting leaves in their mouth to signify that they are like animals. Caregivers worry about their deaf children being teased or bullied. They have to make decisions about exposing them to such behaviours or keeping them isolated (C4).

I will advise the parents not to allow their deaf child to socialize or make friends

because they will stigmatize against him and even call him 'mumu' just like how it is happening to my deaf son, but for my son he doesn't care. C10

Some adults (parents) think that being deaf is contagious and prevent their hearing children from socialising with deaf children in their communities. Some teachers believe that they may give birth to a deaf child if they work with deaf children for a long time. Many families discourage marriage between deaf and hearing individuals, private and public sector employers are reluctant to engage deaf adults and most schools in Ghana - in particular private schools - do not admit deaf pupils for fear of alienating parents of hearing children. The day-to-day emotional and practical needs of caregivers need to be understood and met within these wider societal narratives of what it means to be deaf.

4.3 Language and communication

For some caregivers, the acceptance process involves changes in expectation specifically around communication and language development. Most of the caregivers express their hope that their child will speak and will thus eventually be able to take their place in society (C3). From their perspective, to be something in society, (C6 talks about a 'benchmark' and a 'prominent person') is contingent on being able to speak. The acceptance process involves seeing this differently.

We shouldn't neglect them or discriminate against them. They might be great people to the family or nation in future. (...). We do not neglect him because he cannot hear or talk. C12

Of the 12 caregivers, three are learning to use sign language and have some basic skills. The other nine caregivers are aware of sign language. They have not learned to sign themselves, but they would like to. However, sign language classes are usually associated with the school for the deaf Parents Teachers Association (PTA) meetings that are held three times a year. Because of the location of the schools and cost of transportation, most of the caregivers are not able to travel for these meetings and there is no local training provision.

Caregivers talk about using their own 'home signs' in their communication with their child. This term describes gestural communication systems developed by deaf children and

their families who are not familiar with a conventional signed language (Bloese & Joseph, 2017). Home signs allow for communication and interaction to take place, but caregivers appreciate that there is a difference between these spontaneous signs and the sign language of the deaf community.

I developed our own unique sign language we use to communicate. We didn't conform to the normal sign language, we included everything together, but they still understood me. C7

All 12 caregivers talk about the way in which they blend the use of spoken language with home signs to make meaning. They express doubt about the use of their own sign systems, as not being a recognised sign language.

We only use the Fantse to communicate with him by raising our voice and then sometimes adding signs to it some of the common signs. None of us knows how to sign like the proper sign language but common things like water and stuff the way we use our hand and stuff is common. C5

Caregivers demonstrate their understanding of the need to adjust their communication. They integrate the use of verbal and non-verbal strategies 'speech together with gestures and signs' (C12). They are aware of the need to engage their child's attention and establish eye contact. When caregivers talk about the use of spoken language, they seem uncertain as to how to support development and what to expect. They are uncertain of their child's spoken language abilities and lack understanding about how to foster spoken language skills, other than by raising their voices, focusing on speech sounds and the pronunciation of individual words (C6).

Caregivers demonstrate a partial understanding of language and communication issues. Their responses suggest a polarised view of sign and spoken language possibilities, a generally negative view of sign language and a focus on the development of speech. Being deaf is immediately associated with not being able to talk, and the use of sign language as a potential stigma. Four of the caregivers express hesitancy about using sign language with

their deaf child and anxiety that the use of sign language will limit communication opportunities and further marginalise their child.

My husband was not too happy about the idea of him using sign language because there was no one else around who was using sign language for communicating (...).
C9

I want to interact with my child through spoken language as I see other parents communicating with their children in spoken language. C4

The emphasis in their comments is on being like everyone else and signing is portrayed as an alternative to speech, rather than an additional resource. Caregivers worry about sending their child to a school for the deaf and the implications of this for spoken language development.

(...) I am a bit disturbed because I was told if I send him to deaf school, he might lose the little speech he has because the schools for the deaf only use sign language and gesture as their mode of communication, but I also want my son to talk. C4

Caregivers who have some knowledge and understanding of what it means to be deaf, both in the urban and rural communities, tend to be more accepting of the use of sign language, together with spoken/written languages, home signs and gesture. However, not all caregivers understand and accept such diversity and the education system does not promote bilingual language practices (Opoku et al., 2020). Caregivers who want their child to be able to talk and use the spoken home languages are thus reluctant to engage with the school for the deaf because they associate this educational option with a sign language only approach. This polemic narrative is unhelpful for caregivers in that it undermines the rich communication strategies that they are already developing and obscures understandings of the different ways of being deaf, and diverse approaches to communication (Mprah, 2013).

4.4 Faith

Seven of the 12 caregivers talk about the role of faith in making sense of their situation, and in enabling them to accept what they describe as their 'fate' in having a deaf child. They describe their circumstances as 'God's work' and their faith as a source of strength. They see their children as God's children and, as such, a blessing for the families. Personal or inner strength comes through their faith and prayer and offers a wider connection with benevolence and tolerance.

The Lord who gave you that deaf child will give you the wisdom and the courage to take care of your child. C1

For some caregivers, acceptance is more challenging. Five respondents talk about seeking a cure for their child's deafness, either through God's intervention (prayers, fasting and attending church) or using traditional cures and faith healers. Many caregivers believe that pastors and other religious leaders can intervene and cure their child's deafness and it is not unusual for caregivers to relocate from their homes to church premises in the hope that during their stay their child will be cured.

Caregivers' recourse to traditional cures is also financially driven. The Government of Ghana has developed Community Health Practice and Service Centres and introduced the National Health Insurance Scheme. However, most people in the rural, and predominantly agrarian, communities are unable to pay the yearly subscription fees. People in these communities are equipped with the knowledge and skills to use local remedies and they are more affordable than medical intervention. Such cures are often dispensed by elders in the community and include the use of herbal medicines and body piercings (Kpobi & Swartz, 2019).

Traditional spiritual beliefs about deafness also influence caregivers' responses to having a deaf child. There is a prevalent narrative in traditional Ghanaian society (and in other SSA contexts) that being deaf is curse on the family or local community, and the work of witches or vengeful gods as a punishment for wrongdoing (Kusters, 2015; Mugeere et al., 2015). One caregiver was advised by a spiritual leader to abandon her 'unnatural' deaf child.

One pastor said my child is not a human being, it was a water baby therefore I don't need to stay with that child. Seriously I carried the child in my womb for nine months how can the child be a water baby? C6

Where caregivers are told that children's deafness is the work of the devil or a curse from the gods, acceptance is difficult. This is often compounded by negative social reactions, especially in rural communities where there is less access to formal education, limited understanding of deafness and few or no accessible hospitals or clinics. Education provided by National Commission Civic Education (NCCE) is slowly reaching rural societies, but many caregivers still hide their deaf children from public ridicule and distance themselves from their caring role.

4.5 Support opportunities and constraints

Without newborn screening, the early identification of childhood deafness can be haphazard and dependent on family or community knowledge and experience. Two of our respondents report the discovery their child's deafness as serendipitous: someone in the community noticed a difference in the child's responses to sound or speech. For some caregivers, the first indication is the lack of speech, but these signs are not necessarily associated with hearing loss.

We decided to go to [Teaching Hospital] to check whether he was sick or if there was something under his tongue. C1

For all of the caregivers in this study, confirmation of their child's deafness was late (after 24 months). Following identification, none of the caregivers had received any early professional support, outside of routine clinic visits for hearing tests and hearing aids. To receive a diagnosis of deafness without full information puts caregivers in a precarious position, especially as most are trepidatious about disclosing to others that they have a deaf child.

I don't get any support from the church because I don't usually talk to people about my deaf child (...) I don't personally talk to people that I need support or help for my child.

C4

For two of the caregivers, there were opportunities for support in connection with the schools for the deaf, but because of late identification this was not available until their child was of school age. The support infrastructure through the schools' Parents and Teachers Association meetings and contact with other parents is nonetheless a potential resource that could be expanded to include other family and community members. Caregivers talk about the emotional support that they get from schools, in terms of acceptance and expectations. Through school they have been introduced to examples of prominent and successful people who are/were deaf and are encouraged that their child would also attain such 'distinguished positions' (C8). Two of the parents talked about support from the church where sign language is available. They refer specifically to the Jehovah's Witness group who understand and communicate in sign language.

Financial support is also a priority for caregivers. Caregivers express concern about paying for hearing aids, school fees and materials. Although this is available through municipal and local social welfare agencies, caregivers are often unaware of the resources or find difficult to access them.

Social welfare promised some form of help. There too, you will struggle and be tossed back and forth before your need will be attended to. C8

In addition to school resources, caregivers worry about the cost of hearing technologies. For most, the cost of hearing aids, and especially modern and digital technologies, is prohibitive. They talk about the insecurity of their finances and the use of loans and the need for permanent work. They speak about other ways in which they have sought financial support including via philanthropic organisations. However, there is stigma associated with asking for support and the risk of their situation and their needs being exposed more publicly. The realities for caregivers in this context illustrate the importance of financial assistance alongside information, guidance, and emotional support.

4.6 Expectations of education

All 12 of the caregivers express their wish for their deaf child to be well educated. Ten of the 12 parents spoke of their high expectations and hopes for their deaf children in terms of

education and the future independence that this will bring. Education is described as the way to secure an independent future and employment, notwithstanding the concerns expressed about employment possibilities as a deaf person.

I always pray to God for His help and support so that I can work and support my child to reach a higher level in education. Because he is deaf, I don't know the job opportunities available for him after school. I don't also know an organization that will employ him for job in future because he is deaf. C2

However, caregivers do worry about their child's education. Where the options available involve boarding school, some caregivers worry about separation from their child and what this means for the child socially and emotionally. Some caregivers express an unfamiliarity with the educational context and a lack of understanding of the reasons for their child's learning delay and of the supportive intervention measures. Ten of the 12 parents expressed interest in getting involved with their child's learning and six caregivers talked about supporting their children's education at home. Four of the parents sought outside help or peer tutoring for schoolwork and sign language communication.

5 Discussion: An ecological approach to ECCE

Insights from the interviews, that reveal the day-to-day needs and experiences of caregivers and how these are influenced by the wider context, can valuably inform the development of ECCE in this context.

5.1 Tackling stigma

In this study, the day-to-day proximal experience of caregivers of building communication and a relationship with a new deaf baby are influenced by the external environment where caregivers encounter inhospitable and negative attitudes to deafness and the use of sign language. We are not able to generalise from this sample and there are likely to be differences across rural and urban contexts. Stigma associated with disability in general is reportedly lower in urban contexts where there is a higher level of education, better access to the media, education, and health centres and to the informal community support networks around caregivers. However, almost half of Ghana's population (and the majority of

people with disabilities) live in rural areas that lack these facilities. In these contexts where communal living is common, stigma is more pronounced and more difficult to avoid (Dassah et al., 2018).

In his research with the social work sector in Ghana (Baffoe (2013) finds similar societal barriers to inclusion and calls for country-wide action and education campaigns with the aim of eradicating discrimination and marginalization of people with disabilities. Educational and de-stigmatisation programmes that counter negative attitudes to deafness and sign languages would support the development of ECCE by alleviating the burden of guilt and shame from caregivers and enabling them to build more positive development environments and relationships with their deaf children (Hintermair, 2006).

5.1.1 Changing social narratives of deafness

The visibility of deaf people in society- as leaders, role models and advocates - can change social narratives of deafness and mediate inaccessible environments and discriminatory belief systems and attitudes. There are recent examples of deaf people in Ghana taking leadership roles and developing public awareness across various social media platforms through, for example, performance arts and sport. Several television channels also now devote programme time to disability issues. During sign language awareness week GTV and other media platforms invited the participation of deaf people (lawyers, lecturers, students and successful entrepreneurs). This approach to awareness raising and sensitisation is having an impact on Ghanaian society and attitudes to deaf people. In the wider context deaf-led organisations have been crucial advocates in the global south for sign language recognition, bilingual education, and interpreting rights (De Meulder et al., 2019; Friedner, 2017). This growing community of local and international campaigners for deaf people's rights should be seen as key collaborators in the development of ECCE in this context.

5.2 Language and communication

5.2.1 Deaf leadership

Facilitating contact between caregivers and deaf role models has been shown to be empowering for caregivers and an effective way to support the development of language and communication in the home context (Hamilton & Clarke, 2020; Störbeck & Young, 2016). Following pilot work with families in the USA (Watkins et al., 1998), the mobilisation of deaf

community members as leaders and mentors in ECCE has gained momentum. A call to action by Gale et al., (2021) for involving deaf adults worldwide in ECCE emphasises the need for diverse deaf adults in ECCE leadership as role models and language providers who can contribute specific expertise to the caregivers and families.

The sustainability of this strategy requires investment in mentoring and coaching and deaf leadership that is contextually appropriate. The importation of pedagogies, communication approaches, and sign languages from economically advantaged to LMICs has been shown to be disempowering and disruptive (Brons et al. 2019, Fernandes & Myers 2010). Inclusive models of deaf leadership would need to be sensitive to the cultural and linguistic context for child development, and the existing communicative resources of deaf children and their families. The outcomes of this study suggest that extension of the deaf mentor role to work with communities, community leaders, teachers, and house parents, as well as the nuclear family, would be a beneficial early intervention.

5.2.2 Communication resources

The multilingual nature of Ghanaian society is reflected in the language diversity across the participants in this study. In Ghana, more than 81 different indigenous spoken languages are currently spoken by a population of over 31 million people within over 79 different ethnic groups (Ansah, 2014). Three sign languages have been described in Ghana (Nyst, 2010). These are Adamorobe Sign Language (AdaSL), Nanabin Sign Language (NanaSL) and Ghanaian Sign Language (GhSL). However, the inclusive use of sign language in everyday life has not been socialised apart from the one exceptional example of AdaSL in the Adamorobe community in the Eastern Region of Ghana where the historical presence of a hereditary form of deafness resulted in a high number of deaf inhabitants and emergence of a sign language used between deaf and hearing people in everyday life. GhSL is the sign language of both the rural and urban deaf communities and the most widely used language used in deaf education in Ghana. However, GhSL is not officially recognised as language for deaf people in Ghana and although it is used in schools for the deaf as a medium of instruction there is no official policy on this.

More than eight spoken languages are used in total across the caregiver sample and all the deaf children are in homes where more than one spoken language is used daily. All the caregivers in this study have developed the use of home signs and a range of multimodal

strategies to communicate with their children. This intuitive response to the communication asymmetries in the home is a resource that can be nurtured with caregivers and other family, community members and the use of home signs explained as an integral part of the proximal communication repertoire. This support is time critical and contingent on societal and structural change: Training caregivers in sign language use will only be beneficial if GhSL is visible and accepted as a part of the multilingual linguistic heritage of Ghana.

Caregivers and children have existing communicative resources that can be built into ECCE programmes to facilitate the development of supportive development environment (Yoshikawa & Kabay, 2015). Current approaches to communication support with deaf children and their families are not sufficiently sensitive to the socio-cultural and linguistic heritage of a context such as Ghana. The project team have therefore built on the available expertise to develop context-specific mentoring strategies including short signpost videos for caregivers presented in GhSL with English captions and Twi or Fantse voice-over so that they are fully accessible, and at the same time model multilingual and multimodal communication approaches relevant to the Ghanaian context.

5.3 Support context

5.3.1 *Infrastructure*

The development of an ECCE infrastructure (screening, identification, and follow-up) requires financial resources and long-term investment and the challenges for Ghana and other LMICs for meeting international screening benchmarks are discouraging. However, looking forward to change at the level of infrastructure for deaf children and their caregivers, there are reasons for optimism. Ghana has national legislation for universal access to early childhood education and for the development and protection of fully accessible kindergarten facilities (Wolf et al., 2019). There is also a commitment from multiple stakeholders (including the Ministry of Education, the Ghana Education Service, the Ministry of Health, and the National Council for Persons with Disability) to the rights of children and young people with diverse learning needs to have equitable access to quality inclusive education (Government of Ghana: Ministry of Education, 2013; 2015). This legislative context suggests that there is scope and contextual readiness for the ECCE for deaf children to be addressed.

However, some studies indicate that though existing Government legislation and policies promote the principles and implementation of educational inclusion of all children in

Ghana, caregivers often encounter significant challenges ensuring access to early years education for their deaf children (e. g., Ametepee and Anastasiou, 2015; Opoku, et al., 2020). There is therefore a need to understand the discontinuity between policy and inclusive educational practice, ascertain ways in which processes are monitored, and identify the support needed to sustain recommended ECCE practices across urban and rural contexts in Ghana.

5.3.2 *Community*

When the caregivers in this study talk about their experience of support, they often refer to community leaders and organisations. Their comments reveal community interest and willingness to engage with deaf children and their caregivers and the availability of support from respected members of the community, especially around the dispensing of traditional medicine and therapies (Tabi et al., 2006). The emphasis coming through these narratives on communal relationships and livelihoods is a departure from the discourse of the Euro-Western early intervention guidelines that emphasise the development of the individual and the provision of mainly external support focused on child-parent dyads and the nuclear family. In Ghanaian society that is organised in traditional and collective ways, caregiver and community networks are a potential resource for ECCE (Meeksocha & Soldatic, 2011; Singal & Muthukrishna, 2014).

Faith and traditional beliefs also play an important part in caregivers' lives and strongly influence their first reactions to having a deaf child and subsequent experiences of acceptance. There is a role here for communal intergenerational support and care and for community leaders to positively influence the development environment and mediate local and national ECCE initiatives. This might involve community-based intervention programmes via school, clinic or faith-based centres and the provision of shared spaces in these setting for parents to meet with each other and share their experiences.

5.4 Investment in deaf childhoods

The development of ECCE in this context needs to be responsive to the expectations and hopes of caregivers for their deaf children. Caregivers in this study talk about their hopes for their deaf child in terms of becoming a respected member of the community and society.

In Ghana, early education is seen as beginning of a process of integration into family and society and the development of collective behaviours (Ngaujah & Dirks, 2003; Nsamenang, 2008). This belief is embedded in the traditional African philosophy of Ubuntu - a concept representing communal ideals, human excellence, knowledge, and wisdom (Mugumbate and Chereni, 2019). Ubuntu among the Akan of Ghana is termed, Biako ye – meaning ‘unity is strength’. In Akan, the famous proverb associated with this concept translates into English Language as; ‘It is impossible to break a bundle of broomsticks but easier to break a single broomstick’ [Praye wo ho yi, wokabomu a, embu; na enso, woyi biako a, wobetumi abu mu]. These values are reflected in caregivers’ concerns with the development of children’s independence and their ability to participate in society through education and/or employment.

Caregivers’ expectations and hopes for their deaf children and their own relationships with the educational and school context provide a further important steer for the development of ECCE. Caregivers value education but are confused by educational (communication) choices and lack confidence to support their children’s learning. Caregivers are not empowered to make choices because they so do not have full and balanced information. Much could be done by the education and health professionals to ensure that caregivers are informed and have agency over educational choices. Upskilling the workforce around the education and health of young deaf children and their caregivers would ensure sustainable growth in ECCE expertise exercise and provision.

5.5 Capacity building

Alongside the development of professional practice, the growth of scholarship in ECCE beyond the Euro-Western discourse is crucial. There is a growing body of work that documents the use and development of sub-Saharan signed languages and deaf African perspectives on advocacy, citizenship, cultural experience, education, livelihoods, and participation (Cooper & Rashid, 2015; Edward & Akanlig-Pare 2021). Building on this, contributions from resident deaf African scholars are needed to expand the global science of ECCE to include Africentric perspectives (Marfo et al., 2011).

6 Conclusion

The experiences of this small sample of caregivers highlight the importance of understanding the full influence of the environment on the building of caregiver-child relationships and supportive interaction (Burchinal, 2018; Raikes et al., 2020) as a basis for the development of ECCE. Caregivers in this study are dealing with new experiences of parenting, unfamiliar decisions about schooling, additional financial burdens, and societal discrimination with little or no understanding of their child's deafness and what this means for development and different communication possibilities. These are adverse and impoverished conditions for shaping development opportunities for deaf children that are common to caregivers in LMICs, and current models, based on Euro-Western values, beliefs and caregiving practices, do not connect with African knowledge systems and cultural values (Chataika & McKenzie, 2013).

A greater understanding of the proximal and distal eco-cultural circumstances of childhood deafness is informative and can shape indigenous ECCE processes that integrate with pre-existing practices and knowledge in Ghana, including deaf experience. This work needs to be supported by scholarship that connects the ECCE knowledge-base with the wealth of established literature on child development in Africa and Africentric theories of being (Pence & Marfo 2008; Super & Harness, 2008). An additional focus on training, leadership, and capacity building would ensure the development local ECCE initiatives that take account of the full ecological context of young deaf children's lives and the situated experience of caregivers.

ⁱ For the purposes of this manuscript, the term "deaf" is used as an inclusive term to refer to children and adults, that encompasses individuals with various hearing levels, different linguistic and cultural experiences, and communication preferences. Medialised terms such as 'hearing loss' and 'deafness' are used specifically in the reporting of global statistics, audiological explanations relating to early intervention, and to describe societal attitudes.

ⁱⁱ In audiological terms a disabling hearing loss is a hearing loss greater than 40 decibels (dB) in the better hearing ear for adults (15 years and older) and greater than 30 dB in the better hearing ear for children (0-14 years of age). The normal range of hearing is between 0-10 dB and any loss beyond these audiological thresholds will affect the ability of an individual to hear and participate in a conversation at a normal level of

speech. Without suitable interventions, hearing loss thus poses a significant challenge in the lives of those affected in terms of spoken language and literacy development.

ⁱⁱⁱ The higher reported incidence of deafness among boys is consistent with other studies in Ghana (Adadey et al., 2019).

^{iv} 'Mumu' is derogatory term that means 'dumb' in the Akan language.

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CRediT roles

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