Title: Language development, delay and intervention – the views of parents from communities that Speech and Language Therapy managers in England consider to be under-served.

Authors:
Julie Marshall, PhD, Reader in Communication Disability and Development,
Health Professions Dept. Faculty of Health, Psychology and Social Care,
Brooks Building, Manchester Metropolitan University, Manchester M15 6GX
and Honorary Senior Lecturer, School of Health Sciences, University of Kwa ZuluNatal, Durban, South Africa.
Tel: 0161 247 2581
Fax 0161 247 6364
Email: j.e.marshall@mmu.ac.uk

Sam Harding,
Senior Research Associate
Bristol Speech and Language Therapy Research Unit,
North Bristol NHS Trust
Southmead Hospital
Westbury-on-Trym
Bristol | BS10 5NB
Telephone 0117 41 43957
Email: sam.harding@speech-therapy.org.uk

Sue Roulstone,
Emeritus Professor,
Faculty of Health and Applied Sciences
University of the West of England.
Bristol Speech and Language Therapy Research Unit,
North Bristol NHS Trust
Southmead Hospital
Westbury-on-Trym
Bristol | BS10 5NB
Telephone 0117 41 43957
Email: Susan.Roulstone@uwe.ac.uk

Address for correspondence:
Julie Marshall, Reader in Communication Disability and Development,
Health Professions Dept. Faculty of Health, Psychology and Social Care,
Brooks Building, Manchester Metropolitan University, 53 Bonsall Street, Manchester M15 6GX

Running head: Under-served community views about language

Key words: Language development; language delay, under-served; hard-to-reach, explanatory models, speech and language therapy

Declaration of Interest
None

Abstract
Background:
Evidence Based Practice includes research evidence, clinical expertise and stakeholder perspectives. Stakeholder perspectives are important and include parental ethno-theories, which

1

embrace views about many aspects of speech, language and communication, language development, and interventions. The Developmental Niche Framework provides a useful theory to understand parental beliefs. Ethnotheories, including those about language development, delay and interventions, may vary cross culturally and are less well understood in relation to families who may be considered 'under-served' or 'hard-to-reach' by speech and language therapy services. Who is considered to be under-served and the reasons why some families are under-served, are complex.

Aim: the aim of this study was to describe beliefs and reported practices, in relation to speech and language development, delay and intervention, of parents and carers from a small number of groups in England, who were perceived to be under-served in relation to SLT services.

Methods and procedures: As part of a wider NIHR funded study (Child Talk), seven focus groups (with a total of 52 participants) were held with parents from three communities in England. Topics addressed included beliefs about language development, language delay and parents' reported responses to language delay. Data were transcribed and analysed using adapted Framework Analysis, that also drew on directed content analysis.

Outcomes and results: Four themes resulted, that broadly matched the topics addressed in the focus groups: language development and the environment; causes and signs of speech and language delay; responses to concerns about speech, language and communication; improving SLT. These produced some previously unreported ideas, for example about how language develops and the causes of delay.

Conclusions and Implications:
The findings are discussed in relation to previous literature and the Developmental Niche Framework. Clinical implications include ideas about issues for SLTs to discuss with families and the need to recognise that parents may see themselves as competent facilitators of language. Suggestions are made for future research, including; expanded investigation of a wider range of under-served groups, exploration of who parents consult when concerned about their child's language and how key community figures advise parents in relation to language delay.

What is already known on this subject?
Limited data indicate that parents have a range of knowledge and beliefs about language development, delay and interventions for language delay. Some families in the UK remain under-served by SLT services.

What this study adds:
This study reveals some previously unknown ideas about parents' views about language development, delay and interventions. The findings suggest the need for sensitive discussion with families in order to routinely discover this information and to increase positive engagement with SLT services.

What are the potential or actual clinical implications of this work?

These findings may assist clinical practice by providing ideas about topics to investigate with families, in relation to their ideas about language development, causes of language delay and their ideas about what may help and what they have already tried. The findings underline the need to treat each family individually regardless of any linguistic, ethnic or religious categories into which they may have been placed. Findings also suggests that SLTs should be aware of how families' beliefs may impact on the settings and customs around child rearing that, in turn, may impact on children's communication.

Introduction

Evidence Based Practice (EBP) includes three components: research evidence, clinical expertise and stakeholder perspectives (Schlosser 2004). In relation to pre-school children with speech and language difficulties, in the UK (amongst many other countries), parents and carers are key stakeholders and their views about intervention should be considered. Research to explore the views of parents and carers of children with speech, language, and communication difficulties has increased in recent years. However, parent/carer perspectives may be difficult to ascertain from some groups, including those who, for various reasons, may be considered 'hard to reach' or 'under-served' by speech and language therapy (SLT) services and/or who infrequently take part in research. This paper reports on a study of parents from communities that are not typically included in research and who are considered by SLT managers to be less well represented in their services.

The views of parents are important for a number of reasons. Ethically, it is important to take account of the preferences and perspectives of those in receipt of services in order to avoid paternalism (Siminoff 2013). The role that families' attitudes and beliefs play in a child's developmental progression can be conceptualised in terms of the 'Developmental Niche Framework' (Harkness *et al.* 2007).

The three components of the framework: *customs* (day-to-day routines), *settings* (how parents organise children's social and physical settings) and *caretaker psychology* (parental beliefs or 'ethno-theories') act as mediators between the individual characteristics of the child and the wider culture. Thus for example, the wider culture in which the family lives impacts upon settings, which in turn interacts with the individual characteristics of the child. Similarly, the child experiences the wider culture through the customs and settings of the family. The beliefs and attitudes of the family, are also influenced by the wider culture and in their turn, impact upon the customs and settings provided for the child. This framework can be used to understand if the interaction between the various systems is likely to be a stressor or a facilitator for children's development. For example, if the interactions between the components are coherent and internally consistent with the needs of the developing child, this is likely to facilitate development. Conversely, if there are conflicting components, this is likely to cause or increase levels of stress for the child or family (Harkness *et al*, 2007). There is increasing research to explore the views of parents who have children with speech, language and communication difficulties and related disabilities.

Studies have found variation in terms of whether or not, or at what point in children's development, parents perceive children's language development or behaviour to be problematic (Jegatheeson *et al.* 2010). The process of referral for services as well as the intervention process itself can be filled with uncertainty, fear and difficulty (Lindsay and Dockrell 2004; Lyons *et al.* 2010) and parents have expressed varying views of the value of SLT interventions (Glogowska and Campbell 2000; Lyons *et al.* 2010), as well as some confusion about the nature of interventions (Roulstone *et al.*

2015; Jegatheeson *et al.* 2010). Related to this, studies have also concluded that some parents express feelings of empowerment whereas others feel disempowered, by the process of intervention (Roulstone *et al.* 2015). The participants in these papers however, were predominantly from white, middle class backgrounds and there is relatively little research that explores the views of parents from other groups. We cannot assume that families from all backgrounds will have similar views. Indeed, previous research suggests that people with speech, language and communication difficulties and their families may not all share the same perceptions and explanatory models about communication and communication disability, willingness to engage with services or preferences about the services they want (Marshall 2000; Marshall *el al* .2007). Furthermore, Van Kleeck (1994) used data from across the world to demonstrate that language socialisation is not universal in all aspects. Conversely, Goldbart and Mukherjee's (1999) interviews with parents of children with disability in India, concluded that parents' views on developmental milestones were remarkably similar to western views and that exceptions could often be explained by contextual differences.

Families who are under-represented in research may be those who are also 'under-served' by SLT services i.e. those for whom services are less *available* or less *accessible,* compared to the majority of the population. This might be exemplified by, for example, comparatively fewer services for a particular community group, children not being identified for referral, appointment letters not being written in community languages, families not attending appointments, or not seeing the relevance of intervention for their child (Wylie *et al.* 2013). Anecdotal evidence from the programme of research in which this project was part (Roulstone *et al.* 2015) suggested that SLT managers in England perceived some groups within their local population to be relatively under-served by SLT services. Data are however limited about this issue and there are no national data regarding access to SLT services in England. The complexity of sensitivity and specificity in identifying children with speech and language difficulties across different communities could result in some groups being identified as under-served relative to others. For example, analysis of pupil census data in England showed both under- and over-representation of different ethnic groups in the application of the designation of 'Speech Language and Communication Needs' in schools (Strand and Lindsay 2012). Broomfield and Dodd (2004), in a study of 1100 children referred to one SLT service in England, report that different patterns of diagnosis (expressive language, comprehension of language or speech disability) were associated with socio-economic status; for example, children from poor backgrounds were significantly over-represented in the expressive and receptive language disorder category and under-represented in the speech disorders category. They acknowledge that their findings could be explained by different referral patterns for children from different socio-economic groups or by higher levels of delayed language in some groups related to children's different language learning environments. This could mean that children who could benefit from SLT services are not being identified and others who do not need SLT input are being referred.

The challenges of defining *who* is under-served have been addressed in more detail by Roulstone and Harding (2013). They highlight the difficulties in defining 'under-served populations', as these groups may be heterogeneous, part of diverse communities, religious and/or language groups. Previous research has focused on groups that researchers themselves defined as under-served, such as minority language and cultural groups (Graham and Cameron 2008), rural and remote inhabitants (Verdon *et al.* 2011), elderly people (Dancer and Drummond 1985), and those with low income (McKevitt *et al.* 2005). These studies have shown that the inverse care law (Tudor Hart 1971), where those who most need intervention are least likely to receive it, still holds and that those who have the native language as a second language and are from remote communities, have to overcome more hurdles, such as travelling further to access fewer services (Graham and Cameron 2008; Verdon *et al.* 2011). Thus, services may not be accessed by minority populations and so service providers may not routinely hear or access the views of families from these

communities, and consequently may not adapt services to their needs. The lack of research that captures the perspectives of families from such communities compounds the lack of knowledge about how to make services relevant.

In summary, data on the perspectives and explanatory models of language development, delay and interventions are limited for minority groups, who are also likely to be similar to those groups that are under-served by SLT services. Drawing on the Developmental Niche Framework, the aim of this study was to describe beliefs and reported practices, in relation to speech and language development, delay and intervention, of parents and carers from a small number of groups in England, who were perceived to be under-served in relation to SLT services. The specific research questions were:
What are the beliefs of parents and carers about the process of children's language development?
What are the characteristics of individual children's language development that give rise to concern?
What practices do parents and carers report in response to concern about children's language development?

Method
Ethical approval for this study was obtained from National Research Ethics Service committee – Southmead (11/SW/0228), the University of the West of England and Manchester Metropolitan University.

A qualitative approach was considered the most appropriate methodology for an exploratory study to investigate beliefs and reported practices.

Semi-structured focus groups were used to collect data. The study did not set out to investigate issues for all under-served groups; nor, in adopting a qualitative paradigm, would it make claims that the data would be representative or generalisable. By reporting transparently about the participants, researchers, data collection and analysis, the reader may gauge its transferability for themselves and the extent to which findings may inform interactions with parents and future research.

This study was part of a National Institute for Health Research Programme Grant for Applied Research: Child Talk (Roulstone *et al.* 2015). The overall research programme aimed to investigate individualisation of interventions for children with primary speech and language impairment (PSLI), where PSLI refers to speech and language impairments that exist in apparent isolation from other developmental conditions. It is intended that the findings of this study support the individualisation of interventions, by understanding more about the views and beliefs of groups less frequently engaged in SLT.

Participants
In the absence of objective data regarding which groups do or do not access SLT services, SLT service managers from six case study sites in England that were part of the Chidl Talk project (see Roulstone *et al*. 2015, for further details), were asked to identify client groups within their geographical areas, that they thought fitted one or more of the following categories:
- had poorer attendance rates at SLT than other groups in the catchment area;
- were, for any other reason, under-represented on the SLT service's PSLI caseloads, in comparison to their representation in the general local population;
- were not provided with appropriate services.

A key consideration in the identification of groups was to generate a range of participants whose social/cultural background might be associated with different experiences of language

development and delay. In discussion with the research project's advisory board, three groups were identified:
1. Looked After Children;
2. Children from a range of minority ethnic groups (including specific communities and Refugees and Asylum Seekers);
3. Children whose families are from areas of low socio-economic status.

Access to families in under-served groups can be difficult. It was therefore decided to approach already established community groups. These were recruited based on established contacts and the willingness of organisations to work with the research team. The process was primarily one of convenience sampling for each client group, although within each client group, the aim was to recruit two established groups from different contexts, to increase the range of participants. Details of the six groups who agreed to work with the research team are shown in Table 1.

Table 1: Focus groups and participants

Group information		Number and gender of participants	Other participant characteristics	Number of focus group sessions
Carers of looked after children (CLAC)	i) North East England: Local Authority group. Regular meetings to offer support and training to the carers.	1 male 10 female	Length of fostering experience ranged from 18 months to 8½ years (mean 4 years 4 months); some carers also had their own biological children.	1
	ii) South West England: independent fostering agency. Regular meetings to offer support and training to the carers.	2 male, 10 female		1
Minority ethnic group (ME)	i & ii) South West England: first generation immigrants from one country in Africa. Regular meetings for consideration of social and health and well-being issues	9 female. Attended both meetings	Participants had a range of competence in spoken English. In group (i) the majority of the women understood English, but group leaders acted as informal translators for each other when necessary.

In group (ii) most of the women spoke English but facilitators felt that a small number struggled to understand fully. | 2 |
| | iii) North West England: refugee and asylum seekers from a number of countries in Africa. Regular meetings as a support group. | 11 female | | 1 |

			It was felt to be inappropriate to collect specific data regarding the status/background of individual participants	
Low socio economic status (LSES)	i) and ii) North West England: 2 separate young mothers' groups. Regular meetings as a support group.	ii) 4 female iii) 5 female	All participants were mothers of children aged between 6 months and 2½ years.	1 1

The second author met with the lead contact for each group and discussed possible data collection methods. All groups chose focus groups. Once permission was granted from the organisation for the researchers to run focus groups during their meetings, group members were invited to take part. Informed consent was secured at the first data collection meeting. Focus groups were scheduled to occur during pre-organised meeting times. All focus groups took place in the groups' usual meeting places, that were all non-NHS settings. Participants in each group were known to one other.

The inclusion criteria for each group were broad and required only that each participant was either a parent and/or carer who belonged to one of the groups. Participants were not required to have any experience of SLT. All participants were requested either to have a sufficient grasp of spoken and written English to allow them to understand the participant information sheet and consent form (or a translated version thereof, with some support if necessary) and to take part in a group discussion (again, with some peer support if needed). In the event, the Minority Ethnic (ME) groups included some participants whose English was limited (but who could not be excluded as data collection took place during their normal meeting times). The ME group leaders did not wish to use translators and insisted that they would translate, where necessary. This informal translation slowed the pace of the discussion and in the case of one ME group, a second session was needed in order to cover the topic guide in full (hence there were six groups but seven focus groups took place). In some instances it appeared that translators were summarising the group members' responses to the researchers' questions. It was therefore difficult sometimes to differentiate consensus from diversity.

Data collection
Each focus group was facilitated by the first or last author, who were both SLTs, assisted by two research assistants (RAs) from the research team and, for two groups, a psychologist specialising in work with Black and Minority Ethnic (BME) communities. At the start of each session, the researchers were introduced and the purpose of the session was explained. Informal translation was provided by group members if they deemed it necessary, or where requested. An initial topic guide was developed to address the research questions and explored the components of the Developmental Niche Framework: caregiver beliefs, customs and settings (or practices) and the characteristics of the individual child (see appendix 1). Questions were addressed to participants by the facilitators. Discussion between group members and with the facilitators was encouraged. Topics covered in each focus group varied slightly, due to the time available; furthermore the process was iterative, as the research team debriefed following each session and identified issues that could usefully be pursued in subsequent sessions. The methods used to elicit contributions were thus developed over the seven focus groups. Initially, the facilitator put questions from the topic guide to the group verbally. Additional methods to stimulate discussion were suggested by

the psychologist, based on her expertise and included the use of a fictitious case study that was read to the group and then use to prompt discussion, (see appendix 2); a role play by two researchers; and photographs of children communicating, to stimulate discussion about communication. These additional methods were used with the ME and Low Socio Economic Status (LSES) groups.   All groups were offered written or face-to-face feedback about the findings, at the end of the project.

Data analysis

Data were audio recorded and the English data only were transcribed orthographically, by a RA. The data analysis software programme NVivo (versions 8-10) was used to manage the data. An adapted version of Framework Analysis was used (Spencer *et al.* 2003). The analysis also drew on some of the principles of directed content analysis (Hseih and Shannon 2005), by using prior research and theory to develop the initial codes. Framework Analysis is a well-used, structured method of thematic or qualitative content analysis (Gale *et al.* 2013). The first step was a process of familiarisation with the data, after which a thematic framework was developed by the first author, using a priori themes from the research questions and topic guide, as well as listing any additional key ideas and themes that emerged from the data. The framework was then applied to each transcript in turn by a RA and any further codes were added, if identified. Once each transcript had been indexed, the first author cross-checked the coding, focusing on any additional codes added. Any inconsistencies were resolved by discussion between the RA and the first author. 'Charting' was then used to allow the researchers to look at all the data that had been coded under each theme, check its coherence and to summarise the data for each transcript and theme. The name of each theme was reviewed to ensure that it accurately reflected the data and that it was discrete from other themes. Finally, an adapted 'mapping and interpretation' stage was carried out, focusing mainly on describing the range of data and considering implications. The authors then checked the analysis and resolved inconsistencies by consensus.

Findings

The data were coded under four themes: language development and the environment; causes and signs of speech and language delay; responses to concerns about speech, language and communication; improving SLT. These themes broadly covered the main topics addressed in the interviews and are presented in turn, including illustrative data that demonstrates common ideas expressed across more than one group, less common ideas and also where diversity exists between and within groups.

Language development and the environment
Participants in all groups spoke about how language develops and how that process is facilitated. Their contributions suggested that these parents considered themselves to be competent facilitators of their children's language and gave concrete examples of how they would do this. Some had been exposed to professional advice about facilitating language development. In contrast to their own apparent confidence, participants from both the Carers of Looked After Children (CLAC) and LSES groups gave examples of lack of competence in others – in biological mothers, in the case of CLAC and in fathers, in the case of LSES.

> *he just reads the story like he's reading the paper* (LSES group 1)

They talked easily about strategies they believed support language development and justified their views. Many of these strategies were consistent with typical SLT/professional advice. For example, the CLAC groups stated that children need early and frequent input, should be talked to, should not be criticised, and that socialisation and engagement should be encouraged. Two groups discussed stories and reading.

It's due to us as parents to encourage talking to the children, to prompt them to start talking early, things like reading them books, telling them stories… (ME group 3)

Using lots of eye contact and talking to babies were suggested. One group talked explicitly about the value of play and singing was explored by two groups.

if you're singing the nursery rhymes, they're learning the words in a happy way (LSES group 2)

One ME group's ideas about features of the environment that encourage language included eating with children, keeping the child close to the mother, children talking to each other and using actions to support spoken language. Other strategies discussed by one or more groups included having space, trips out of the home and using exaggerated intonation:

the way you say things helps 'em remember the words (LSES group 1)

Television occupied a significant part of the discussion in all groups apart from the CLAC, with mixed views being expressed between and within groups. One ME group viewed television positively and one had mixed views.

He loves CBBC, but my husband he say 'half an hour max TV, because it is no good for kids' (ME group 1)

One of the LSES groups explained why they generally view TV positively, with some qualification about appropriate programmes and the positives of exposure to new vocabulary.

*not everyday words that we'd say 'oh look that's a flamingo', cos you're not going to say flamingo at home are you (*LSES group 2)

Additional ideas expressed by individual groups included the possible negative impact on language development of bilingualism, regional accents and non-standard pronunciation of English. Two groups stated that they regarded imitation by the child as positive and one group reported being advised to reduce asking questions to their children and they found this challenging.

Causes and signs of speech and language delay
Ideas expressed about the causes and signs of speech and language delay varied between participants and included language deprivation and both causative agents that have been previously reported and those that have not. Descriptions often were broad:

Well their background has a huge impact on their speech (CLAC group 1)

and related to their own experiences. The focus of the discussions in the CLAC groups was on the impact of atypical environments on children's language, e.g. children who had been neglected, lacked experiences, adult input and had reduced need to communicate. Participants from both CLAC groups referred to the impact of one child 'talking for' another:

he just wouldn't talk at all, because she'd done all the talking for him (CLAC group 1)

They considered that previous discouragement from speaking impacts negatively on children's language development*.*

There are a lot children who are fostered, I think a lot of it's the same, either they've been ignored, nobody asking their opinion, nobody's wanted their opinion. And all these signals come from every different direction (CLAC group 2)

In contrast, the ME and LSES groups, described both intrinsic and environmental causes of delay. Beliefs about causes includes both those that are accepted by/familiar to SLTs, as well as those that are not. For example, the LSES group reported intrinsic causes including hearing loss, cleft palate, other disabilities and 'psychological difficulties' (the child is '*excited*' or *'mad'*), which may result in what appeared to the mothers to be non-fluency. Environmental factors, including the use of 'baby talk', were discussed, with members of one LSES group considering it to be a negative influence, although they were not clear if they believed that 'baby talk' *caused* speech and language delay:

I'm not saying it's wrong but I don't want xxxx being taught I don't like it. (LSES group 2)

They discussed the negative impact of dummies (pacifiers/soothers).

if you try and say S with your mouth shut, or something in your mouth, you can't do it (LSES group 1)

and reported viewing lack of parental language input as negative.

I think some mums just don't realise how like, how it can affect a child if you don't speak to them from a young age (LSES group 1)

The ME group also suggested a range of causative agents, some of which have been previously reported and are indeed potentially associated with language impairment, for example genetics, prematurity, being a 'slow learner', pre-natal maternal alcohol consumption; some previously reported but not evidenced causes e.g. inability to lift the tongue, laziness, learning two languages, and bewitchment; and some that may not have been previously reported e.g. injections, global warming, war, English weather, air pollution and lack of fresh, organic food.

*the problem we have with children speech is that, children that can't talk, is because of the war, the food we eat, and the weather (*ME group 1)

The refugee and asylum seekers group felt that the social context for this community in the UK may have a negative impact on language development, for example small, fractured families, stressed, withdrawn, isolated or depressed mothers, who may not talk to their children a great deal, tension at home and exposure to multiple languages.

it could be like the mother's depressed and the mother is not even having time to spend time to read to her, to spend time to, to help her with anything at all, so probably could be an issue (ME group 3)

The ME group talked about 'God testing' parents by giving them child with a disability and the possibility that having a child with disability is a punishment for committing a sin. Nonetheless, the group members agreed that mothers were not directly responsible for a child's disability difficulties and guilt was not expressed.

That is right, no guilt, it comes from God and you just try your best and then if it doesn't work then that is it. We always think that anything comes to us, if you are sick or your

*child is sick, or anything happen in your life, you have to accept because you don't, we don't question (*ME group 2)

Relatively few ideas were given about *signs* of speech and language delay. The CLACs referred to lack of attempts to communicate or adults not engaging with children.

It's just not natural human behaviour for a small child not to want to babble (CLAC group 2)

Amongst the ME groups frustration and lack of concentration were given as signs of speech and language difficulty and one participant reported on a traditional view that if a child cries for its mother *'ma ma ma ma'* it means there is 'something wrong' but if it cries for its father *'da da da'*, there is no significant problem. The age at which concern would be raised ranged from six months to 2 years, although one participant commented:

*Then you can start worrying, but then again we are in denial because they say that your grandfather didn't talk until he was 6 years old (*ME group 1*).*

Responses to concerns about speech, language and communication difficulties
In all groups participants talked about what they would do and who they would talk to, before or in addition to consulting health care professionals, should they have concerns about a child's language development. The responses of CLAC groups focused on exposure to language and differed from the other two groups and so are described separately. The ME and LSES groups gave both responses that SLTs might recommend, as well as those that are not routinely recommended, as well as suggesting a range of people who may be consulted.

The CLAC group described mainly supporting children whose communication environment, they believed, had been less than optimal before they were placed in care. They felt that providing a more positive communication environment could compensate for and reverse prior negative impacts and commented on the speed with which children in their care progressed with this input, thus emphasising its importance. They described the efforts they made to try to support the development of social/pragmatic communication skills with children who had lacked previous opportunities to develop important communicative functions, for example learning to argue, contradict and interact.

They don't get the opportunity to develop that skill, um not necessarily a debating skill but a conversational skill where it can be safe to disagree. (CLAC group 2)

They also described instances of looked after children's language regression when they had contact with their birth parents. They did not always distinguish between what they provided for children with delayed language and for any child coming into their care. They described '*talking all the time*', discouraging others from talking for the child, using picture cards, games, reading and singing.

Some CLAC participants described supporting children with speech and language difficulties without accessing SLT.

For me it would only be something that I couldn't deal with so if it was a child stuttering or stammering… tell them to slow down and listen no matter how long it takes. I haven't had a need to go seek other professional help. (CLAC group 2)

For the ME and LSES groups, a wide range of suggestions were made about what mothers or other family members would do, in order to help a child with a disability (they did not always specify speech and language difficulties). Again, these included strategies that SLTS may typically recommend,

such as signing and use of body language, repetition, ensuring they have eye contact with their child in order to improve attention, repeating a mis-pronounced word correctly, using facial expression to emphasise meaning, exposing their child to other children, spending time with the child (including one-to-one time). Strategies less typically recommended by professionals included: physical support, telling a child to slow down or completing a sentence if a child is non-fluent,

> *introduce 'em to other children but not children who are slow at speaking…so they can play with them, cos I think kids interact with kids better than adults* (LSES group1)

> *She will always support him and bring him what he wants and so for example he is playing with a toy and it rolls away, she will always support him in getting what he wants (*ME group 1)

One ME participant described having being told that medication, in the form of a tablet, could be given to cure/treat a non-speaking child. There was no consensus regarding whether a child would be hidden from other community members or if the mother would be in denial about the child's difficulties. Participants from the LSES group talked about the need for early referral versus, a 'wait and see' approach and their concerns about being 'judged by authorities' and how this influenced their help-seeking behaviour.

Mothers, friends and neighbours were all mentioned as people who may be consulted about their experiences and for their advice.

> *we have a saying that '100 people will advise you when you are sick' (ME group 1)*

One ME group reported that a child may be taken to the mosque, 'spiritual man' or pastor. At the mosque the parent may receive instructions from an Imam, passages from the Qor'an may be read over the child, or over water/honey that is then given to the child, or the child will be prayed over. In response to follow-up probes, participants agreed that cutting of the lingual frenulum occurred and that honey that has been blessed by the imam, maybe given to the child to 'taste'.

ME participants reported three groups of health professionals that they would consult: General Practitioners, Health Visitors and SLTs, with one group reporting that they may consult doctors outside the UK. Isolation was reported to have a detrimental effect on help-seeking for one of the communities interviewed, together with a limited understanding of UK services, and a lack of awareness about SLT, that may limit interactions with and responses to services.

> *we don't know how this country runs, we don't know anywhere where to get advice, you don't know whom to ask. (*ME group 3)

Participants who were first generation immigrants to the UK reported that number of factors that may influence their help seeking. These include lack of (exposure to) SLT in their country of origin, lack of speech not being seen as a priority as is it not seen as a 'sickness' and that not all communication disabilities are viewed equally (e.g. stammering may not be viewed as a serious problem). Patterns of help seeking are thus varied, as are the points at which / reasons why people reported that they would seek help.

Improving SLT
The final theme covers a number of suggestions for improving access to, and engagement with SLT services, included rapid access and improved ways to interact with families. The CLAC group suggested that, for looked after children, there should be faster access to SLT; assessment should be carried out in the home and that some SLTs need greater understanding of individual children,

their family situations, likely previous experiences and needs.

> *we had a speech therapist in, and the problem is that she saw him at school in his school uniform she didn't see him at home (CLAC group 2)*

Parents from all groups wanted professionals to take time to get to know them, their child and their context, in a non-judgemental way, before making judgements and that professionals should not make assumptions about how a mother is already behaving.

> *knows me and knows xxxx, so they know like that I'm doing everything right and xxxxx's still not talking* (LSES group 1)

One ME group suggested that the following actions would encourage families to feel more positive about health care professionals: using appropriate body language (e.g. facial expression, shaking hands), asking families for their views in a way that acknowledges that some families feel that the healthcare professional (and not the parent) is the expert and that is why they are consulting him/her.

Discussion

The discussion considers the findings from this small convenience sample of under-served communities in the light of the Developmental Niche Framework and with reference to other literature, particularly studies that have focused on parents' perspectives. Implications for practice and further research are discussed, with due consideration of the limitations of this study. The value of these findings for future practice are in providing ideas about topics to investigate with families, rather than providing definitive evidence about specific groups' beliefs.

It is possible to see how parents' ethno-theories might impact upon and interact with their child's language development, in the way that parents structure the child's settings and through their customs of interaction. For example, parents talked about children needing and benefiting from other children's input (an ethno-theory) which might lead a parent to organise nursery attendance (the child's setting) or to give responsibility for playing with a child to an older sibling (typical interactions or customs). Parents' assumptions about the underlying cause of a child's difficulties may be related to their beliefs (ethno-theories) about the mutability of the impairment and their own potential as parents to effect changes in their child. For example, conducting parent-child interaction therapy with a parent who already feels that they have caused or contributed to their child's difficulties, may add to their existing burden of guilt, unless carried out sensitively. Conversely, a parent whose approach is to accept an impairment fatalistically, could either be positive about their role as a supporter of intervention or alternatively may not believe in the use or power of intervention.

There were also examples of how the wider culture influenced customs such as help-seeking behaviours, for example, where members of a particular culture would consult an Imam before accessing professionals. Similar to Jegatheeson *et al.* (2010), lack of familiarity with the local health system was also clearly influential, as some parents had no experience of SLT.

A common approach reported in this study was to seek (or receive) advice from friends or relatives, whereas Skeat *et al.* (2010) from their community cohort study in Australia, found that parents of children aged under four years, with speech and language impairments sought help mainly from maternal sources and child health nurses, with SLTs being approached more often as the child got older. Further research is needed to understand who (else) parents consult (e.g. grandmothers, community elders, traditional healers, religious figures), the knowledge and skills of those groups, what advice is given by them and whether there is a need to further educate the community at large and those from whom parents seek advice.

Negative views about bilingualism and regional/social language variation were apparent for some groups and there was some suggestion that some parents regarded television viewing as supportive for learning of English. This is worthy of further investigation and may suggest a continued need for information about supporting bilingualism (Pert and Stow 2015).

A number of the ideas about influences on language development and delay, for example the influence of global warming and war, may be unfamiliar to SLTs and are worthy of probing with parents, despite it being tempting to dismiss them as idiosyncratic. Strategies mentioned by parents, although lacking the specificity of those used by SLTs within parent-child interaction therapy, are consistent with the recommendations of professionals. For example, one group highlighted the importance of playing with your child, whereas SLTs would perhaps talk about specific strategies to be used whilst playing with your child.

The amount of discussion and debate demonstrate both the difference and commonality between and within these three outwardly homogenous groups and demonstrate the diversity of parents' ethno-theories. As the sample was small and expression of some ideas may have been affected by some participants' proficiency in spoken English, further research on the range of views held by members of different communities could help to guide SLTs towards potentially useful topics to probe with families. The *diversity* of views expressed strongly indicates the need to discuss beliefs about language development and about speech, language and communication difficulties, with every family and not to make assumptions based on their membership of a specific ethnic, religious, socio-economic or other group.

Central to the Developmental Niche Framework is the individual child and the dynamic adaptation of the child and their environment. The way that parents respond to an individual child was not explicitly explored within the focus groups, but the importance of professionals getting to know the child as well as the parents and context, and the benefits of professionals visiting children in their own homes, was stressed by parents. Discussion with families about their ideas can reveal the logic, power and explanatory value of such beliefs, which may, in turn, be a vital step in establishing a successful working relationship with families. As recognised by Marshall *et al.* (2007) and Glogowska and Campbell (2004), parents have existing views and beliefs and do not arrive at professionals as 'blank slates'.

Parents in the current study, across all groups, presented their views about how best to support language development in a fashion that suggested they felt competent as language facilitators. The CLAC groups expressed a view that, for the children typically being placed with them, they felt experienced and competent to deal with their issues and did not usually need to consult SLTs. Commenting on the lack of competence of others served to contrast with and highlight participants' perceived competence. In a therapy context, parents may already feel uncertain; SLTs could easily undermine a parents' sense of their own agency. Empowering parents to adopt positive roles within therapy is a stated aim of SLTs (Roulstone *et al.* 2015).

Klatte & Roulstone (2016) concluded that therapists' skills are crucial to the effective engagement of parents and Auert *et al.* (2010) pinpointed the need for appropriate information and effective communication from SLTs. Similar to the families in Jegatheeson *et al.* (2010), who were looking for warmth and personal relationships from professionals, parents in this study were clear that they wanted professionals to take time to get to know them and their child in a non-judgmental and friendly fashion.

Finally, further discussion is needed within the SLT community, about how to respond to inaccurate beliefs, particularly those that may not support language development. Andrews and Andrews (1990) stated that intervention is only effective where it is congruent with existing family

dynamics, but there is a need to consider how to work with families if such congruence is not possible, for example if their espoused views could have negative impacts.

Due to the small sample size and challenges encountered with translation within the discussions, it was challenging to probe individual participants' explanations of their comments. This meant that the data did not lend themselves to more interpretive levels of analysis. Nonetheless, the data still have value as one of the only studies in SLT to address the perspectives of families who are frequently excluded from research studies.

Conclusion

'Under-served' groups are diverse, with different groups being identified by the individual SLT managers in this study. There may be other groups, not identified in this research, who are perceived by SLT services to be under-served. There may also be groups that SLT services have not identified as being under-served, but who themselves feel under-served, and yet others who may not be seen (by themselves or by SLT services) as being currently under-served by SLT services (e.g. parents with (mental health) disabilities). Local and national data are clearly needed regarding access to SLT services in order to begin to identify service reach. Furthermore, understanding how different groups identify and respond to speech and language delay could lead to a better understanding of prevalence and risk within these groups.

In the interim, one positive change would be for all SLTs to be aware that family beliefs may impact upon the communication environment and families' abilities to engage with parent-child interaction interventions. Some of those impacts have been explored here but further research is needed fully to understand how these variations impact upon children's developing communication and on language impairment. SLTs need to be competent at eliciting information from families, armed with sufficient cultural knowledge to support that discussion.

The use of the Developmental Niche Framework to understand participants' responses in this study has highlighted the relationship between parents' ethno-theories and how parents might respond in clinical contexts. The framework could be used in clinical practice to structure discussions with families and research to investigate the impact of this on parent satisfaction with initial assessments, would be valuable.

This study of three groups of parents from communities viewed by SLT managers to be under-served, has emphasised the heterogeneity of perspectives within and across groups. This means that understanding parental perspectives about language development and delay needs to be built into the assessment and intervention planning process. Such developments are likely to result in improved experience of SLT services for families and perhaps also improved patient outcomes, although these assumptions require further research.

Topic guide and prompts

Participants were asked to give their views on the following topics:
- How do children learn to talk?
- What are the important influences on children learning to talk?
- What are the signs of a child having difficulties learning to talk?
- At what age does lack of speech/language cause concern?
- Why do you and members of your family/community think that some children may have difficulties learning to talk?
- How would you and members of your family/ community respond if a child had difficulties learning to talk?

When the CLACs were identified as an underserved group, an additional question was asked, as many of the CLACs had experience of SLT:
- What are CLACs' view on their experiences of and barriers to, SLT?

Appendix 2
Fictitious case used in one focus group

Hello, my name is Mariam. I am 30 years old. I came to Britain five years ago and have lived in Manchester since then. I came with my husband and my daughter Ana, she is now 8 years old. When we arrived, I was pregnant with my son Adam who is now four years old, and later I had my daughter, Sara who is now two and a half years old.

My husband left me two years ago and now lives in Bolton. He comes to visit us every month and spends some time with the children. I miss my mother a lot. She is still living back home and I have not seen her since I left. We talk on the phone at least once a week but there are times when she does not have credit and I cannot help her. I pray that God will provide for her.

Back home, I qualified and worked as a nurse but I have not been allowed to work since I came to this country.

I take my daughter Sara to the mother and toddler group in the children's centre and we go to a group for asylum seekers every two weeks.

We live in a small flat with two bedrooms and there is no garden. I got some toys for the children from a charity and they also gave us a TV.

I am worried about Sara because she does not talk at all. She makes a few sounds and points at things, but her brother and sister were talking much more by her age.

Typical questions following the presentation of this case study were:
'Is this a believable story about a child not talking?'
'Thinking beyond Mariam's situation, what other ideas would you have about how children learn to talk?'

References

ANDREWS, J. and ANDREWS, M., 1990, Family based treatment in communicative disorders (Sandwich, Ill.: Janelle Publications).

AUERT, E., TREMBATH, D., ARCIULI, J. and THOMAS, D., 2012, Parents' expectations, awareness, and experiences of accessing evidence-based speech-language pathology services for their children with autism. International Journal of Speech-Language Pathology, **14(2),** 109-118.

BROOMFIELD, J. and DODD, B., 2004, Children with speech and language disability: caseload characteristics. International Journal of Language and Communication Disorders, **39(3),** 303-324.

DANCER, J and DRUMMOND, S.S., 1985, Communications problems of the elderly: a survey. Nursing Homes. **34(3)**, 26-29.

GALE, N., HEATH, G., CAMERON, E., RASHID, S and REDWOOD, S., 2013, Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMCMedical Research Methodology, **13(117).**

GLOGOWSKA, M. and CAMPBELL, R. 2000, Investigating parental views of involvement in pre-school speech and language therapy. International Journal of Language and Communication Disorders, 35 (3)**,** 391–405

GLOGOWSKA, M. and CAMPBELL, R., 2004, Parental views of surveillance for early speech and language difficulties. Children and Society, **18**, 266-277.

GOLDBART, J. and MUKHERJEE, S., 1999, The appropriateness of Western models of parent involvement in Calcutta, India. Part 1: parents' views on teaching and child development. Child: Care, Health and development, **25(5),** 335-347.

GRAHAM, S. and CAMERON, I.D., 2008, A survey of rehabilitation services in Australia. Aust. Health Rev. Publ. Aust. Hosp. Assoc, **32**, 392–399.

HARKNESS, S. SUPER, E., SUTHERLAND, M., BLOM, U., MAVRADIS, J. and AXIA, G., 2007, Culture and the construction of habits in daily life: implications for the successful development of children with disabilities. Occupation, Participation and Health, **27,** 335-405.

HSEIH, H. and SHANNON, S., 2005, Three Approaches to Qualitative Content Analysis, Qualitative Health Research, **15(9),** 1277-1288.

JEGATHEESAN, B., FOWLER, S. and MILLER, P.J., 2010, From symptom recognition to services: how South Asian Muslim immigrant families navigate autism. Disability & Society, **25 (7**), 797-811

KLATTE, I. S. and ROULSTONE, S., 2016, The practical side of working with parent-child interaction therapy with preschool children with language impairments. Child Language Teaching & Therapy. Early online April. doi: 10.1177/0265659016641999

LINDSAY, G. and DOCKRELL, J. E., 2004, Whose Job Is It? : Parents' Concerns About the Needs of Their Children with Language Problems. The Journal of Special Education, **37,** 225-235.

LYONS, R., O'MALLEY, M., O'CONNOR, O. and Monaghan, U., 2010, 'It's just so lovely to her him talking': Exploring the early-intervention expectations and experiences of parents. Child Language Teaching and Therapy, **26(1**), 61-76.

MARSHALL, J., 2000, Some reflections on the cultural influences on the identification and habilitation of children with speech and language difficulties. International Journal of Disability, Development and Education, **47 (4),** 355-369.

MARSHALL, J., GOLDBART, J. and PHILLIPS, J., 2007, Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. Int. J. Lang. Commun. Disord, **42,** 533–555.

McKEVITT, C., COSHALL, C., TILLING, K. and WOLFE, C. 2005, Are there inequalities in the provision of stroke care? Stroke, **36,** 315-320.

PERT, S. and STOW, C., 2015, How can we best assess the language skills of bilingual children? How can we offer therapy for bilingual children in their home language in light of limited resources? Bulletin of RCSLT, March, 20-21.

ROULSTONE, S. and HARDING, S., 2013, Defining communication disability in under-served communities in response to the World Report on Disability. Int. J. Speech Lang. Pathol. **15**, 27–31.

ROULSTONE, S.E., MARSHALL, J.E., POWELL, G.G., GOLDBART, J., WREN, Y.E., COAD, J., DAYKIN, N., POWELL, J.E., LASCELLES, L., HOLLINGWORTH, W., EMOND, A., PETERS, T.J., POLLOCK, J.I., FERNANDES, C., MOULTRIE, J., HARDING, S.A., MORGAN, L., HAMBLY, H.F., PARKER, N.K. and COAD, R.A., 2015, Evidence based intervention for preschool children with primary speech and language impairments – an exploratory mixed methods study. Programme Grants for Applied Research Report 0109-10073.

SCHLOSSER, R., 2004, Evidence-based practice in AAC: 10 points to consider. The ASHA Leader, **22(6-7),** 10-11.

SIMINIOFF, L. A., 2013, Incorporating patient and family preferences into evidence-based medicine. BMC Medical Informatics and Decision Making, **13** (supplement 3), S6.

SKEAT, J., EADIE, P., UKOUMUNNE, O. and REILLY, S., 2010, Predictors of parents seeking help or advice about children's communication development in the early years. Child, Care Health and Development, **369(6),** 878-887.

SPENCER, L., RITCHIE, J., LEWIS, J. and DILLON, L., 2003, Quality in Qualitative Evaluation: a framework for assessing research evidence. A Quality Framework. London, UK: Strategy Unit Admir. Arch Mall.

STRAND, S. and LINDSAY, G., 2012, Ethnic disproportionality in the identification of speech, language and communication needs (SLCN) and autism spectrum disorders (ASD). London, UK: DFE.

TUDOR HART, J., 1971, The Inverse Care Law. The Lancet, **297(7696),** 405-412.

VAN KLEECK, A., 1994, Potential cultural bias in training parents as conversational partners with their children who have delays in language development. American Journal of Speech Language Pathology, **3,** 67–78.

VERDON, S., WILSON, L., SMITH-TAMARAY, M. and McALLISTER, L., 2011, An investigation of equity of rural speech-language pathology services for children: A geographic perspective. Int. J. Speech Lang. Pathol, **13,** 239–250.

WYLIE, K., McALLISTER, L., DAVIDSON, B. and MARSHALL, J., 2013, Changing practice: Implications of the World Report on Disability for responding to communication disability in underserved populations. International Journal of Speech Language Pathology, **151**, 1-13.