

***Barkerend Sure Start Programme
Local Evaluation***

A qualitative study to investigate factors affecting
the efficiency of the physiotherapy home visiting service

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SUMMARY

The Barkerend Sure Start Programme developed a physiotherapy home visiting service in 2001. The service was part of a wider initiative that aimed to promote earlier identification and assessment of special care needs. Its remit was to establish more locally-based services in an area where the majority of young children came from families of Pakistani origin. The present study aimed to evaluate this service using a qualitative methodology in order to explore in-depth the views of relevant health professionals and of local South Asian mothers. The approval of the Local Research Ethics Committee was obtained. A trained bilingual researcher conducted a series of interviews, which were tape recorded, transcribed and analysed thematically.

While the discussion sessions with the health professionals were simple to arrange, organising focus groups for the mothers of children with special care needs proved so difficult that the researcher had to resort to a series of one-to-one home-based interviews. Parents with young children with special care needs generally appreciated the home-based service being offered, the access to bilingual physiotherapy assistants and the quality of the explanations and the care available. Added value included identification and support in the home-based setting in relation to other family needs. The majority of mothers preferred the 'local', 'friendly', physiotherapy service provided through Sure Start compared with the mainstream provision because 'it was convenient' and 'saved time'.

The health professionals and physiotherapy assistants generally agreed that the locally-based service had distinct advantages for families, although there was concern that some parents did not understand or value the service sufficiently. Disquiet was expressed about delays in referring into the mainstream physiotherapy service through the former GP-based primary to secondary care route - which was now being by-passed in Barkerend through the wider-access Sure Start arrangements. The lower DNA rates incurred through home visits compared with mainstream services were seen as a definite efficiency gain.

Cultural and linguistic barriers were thought to be a potential source of difficulty for some families in understanding and being able to take full advantage of the service, with a need for health education in order to raise awareness in local South Asian communities. The work of the bilingual physiotherapy assistants was highly valued but since recruitment appeared to be problematic, this issue needed to be urgently addressed. Recommendations have been developed to inform changes in service delivery and any accompanied health promotion programmes.

BACKGROUND

Barkerend Sure Start is Bradford's trailblazer programme, having received approval from the Sure Start Unit in April 2000. It is located in one of Bradford's most disadvantaged areas. According to the 2001 Census for Barkerend and Thornbury, 42% of the population were of Pakistani origin, 5% were Bangladeshi, 8% Indian and 39% were white, plus a small African Caribbean population. However, due to differential birth rates, analysis of the Child Health Database in 2003 indicated that among the 1600 families resident with children aged 0-4 year, two thirds were of Pakistani origin, 15% were Bangladeshi and 11% were white, indicating the high proportion of young children of South Asian origin in the neighbourhood.

The Delivery Plan¹ perceived some of these communities to be self-contained and in need of specially targeted services. It was also considered essential that activities should be culturally appropriate and that the very specific needs of minority groups be met within the over-arching objective to improve social and emotional development, to improve health, to improve the ability to learn and to strengthen families and communities.

Barkerend Sure Start is geographically located within Bradford City PCT, which has one of the highest levels of health inequalities recorded in England. Against this background, health and access to health care were identified as key issues for Barkerend Sure Start at an early stage of the programme's development. A need was identified for better access to specialist services, with Sure Start bringing added value by:

- Promoting earlier identification and assessment of special needs in pre-nursery aged children
- Expanding under-resourced services
- Basing services locally, to increase accessibility
- Using seconded staff, where possible, so that Sure Start principles could be 'adopted' by mainstream services, where appropriate
- Engaging some specialist services on a sessional basis, according to need.

Background information also suggests that the proportion of children identified with special care needs is higher among the Pakistani community². Higher levels of disability have also been recorded among adult members of the South Asian Muslim population in Britain³.

Barkerend Sure Start aims to contact 100% of families with young children in their locality within the first 12 months of birth. By this means, or through earlier referral from the mainstream services, young children with special care needs can be picked up at an early stage and supported to use appropriate local services. Specialist Sure Start Programme services available in Barkerend include community pediatrics, home safety, specialist family support, counseling and physiotherapy, all of which can be of great value to such families.

Paediatric physiotherapists work to maintain and maximise the physical potential of the disabled or developmentally delayed child. This includes rehabilitation following impairment due to injury, operation or disease processes. Physiotherapists aim to aid, stimulate and enhance child development whilst facilitating growth of the child's functional performance⁴. Prior to the development of Sure Start services, carers with young children with special care needs would normally need to escort them for an assessment at a Child Development Centre (CDC)-based paediatric consultant at St Luke's Hospital (about three miles away), in order to be referred on to mainstream physiotherapy services. The majority of these mainstream services were also provided at the same hospital, although a limited number of district wide home visits were also made available for a few children under 12 months of age. The need to keep appointments with the hospital-based services could present challenges and stresses for these families due to difficulties with transport, in terms of time and cost, especially if repeated visits were required. There is no direct bus route between Barkerend and the hospital-based physiotherapy service. If there were other young children in the family, domestic arrangements would require that their care needs also be accommodated around these visits.

Early consultation for Barkerend Sure Start revealed a need to target children's special care needs within Barkerend. Good quality health services should be available to all. The right of the individuals with disabilities to share the same quality of life as anyone else in the society needs to be addressed⁵. Parental frustration resulting from the lack of resources available to assist parents of children with special needs experiences has been reported elsewhere⁶. While there are many disorders in which early diagnosis does not improve outcome, appropriate measures can enable the child and family to cope with disability more effectively. The provision of services can help reduce parental frustration and isolation and support the child to make the most effective use of those functions and abilities which have been preserved. For instance in the case of cerebral palsy, early physiotherapy can prevent or delay the progression of postural deformities and contraction⁷.

There are now a number of initiatives developed to engage these families. The local physiotherapy team aims to encourage parents, including those with children with special care needs, to participate in infant massage activities organised by the Sure Start health visiting team.

In addition, they provide local facilities for parents to meet and share their concerns and ideas and gain support from each other, as well as for their children with special physical needs to meet and play. Also, the Barkerend Physiotherapy Home Service Programme (BPHSP) offers physiotherapy for young children with special care needs either in a domestic setting or at a community setting, such as a nursery. The aims and objectives of the Physiotherapy service for the children with special/ additional needs living in Barkerend Sure Start catchment area are to:

- Assess the children and evaluate therapy needs
- Provide an activity programme for each child
- Refer children to members of the multidisciplinary team where appropriate, e.g. through Fast Track Clinic
- To work with the child within the home setting
- To support and work with the child in nursery and school.

In Barkerend, referral to the BPHSP now occurs via health visitors or a locally-based community paediatrician or local GPs or via the original Child Development Centre (CDC) arrangements. The service is provided by an English speaking physiotherapist (10 hours), assisted by two bilingual physiotherapy assistants (who speak Urdu and Punjabi), each working for 20 hours per week. The service started in 2001.

The local community has very diverse linguistic and cultural needs and similarly the range of disabilities is very varied. Initially, 29 children were identified and in 2003, that number increased to 33. The current caseload (2004) consists of 44 children with various categories of special needs, including delayed development (N=19), cerebral palsy (N=8), specific syndromes (N=2), foot problems (N=4), degenerative disorders (N=2) and other miscellaneous conditions (N=9). Their ethnic composition is equally varied:

Pakistani:	23	Bengali:	8
Gujarati:	5	Pathan:	4
White British:	3	African:	1

Of these, 14 parents were in need of language support, which is provided by the two trained physiotherapy assistants capable of communicating in Punjabi and Urdu languages with the aim of increasing parental cooperation and compliance. The initial assessment is made by the senior physiotherapist, who prescribed a programme of interaction for each child. During subsequent domiciliary

visits, physiotherapy is provided by the physiotherapy assistants who interact with the child and parents. Physiotherapist and assistants meet regularly to review the cases and monitor individual progress.

Part of the function of a local service is to make it easier for families to access and to make the service more efficient by avoiding failed appointments inherent in a hospital-based service. An internal audit of BPHSP carried out between July 2002 and April 2003 to monitor the DNA (did not attend) rate for children involved in the Sure Start project revealed that 7.6% of appointments were missed. Of the explanations provided by the families, 72% forgot, 7% were unwell, 7% had a GP appointment and a further 7% were late back from a trip out. A similar audit undertaken in the hospital-based service revealed that the DNA rate was 19%.

The BPHSP is a unique service facing challenges in reducing inequalities in an area of high need. For the service to work efficiently, young children should be referred at an early stage, the providers need to feel able to provide a high-quality service under local, rather than hospital-based conditions, and the users/carers must value and understand the need for the service in order to maximise compliance. In Barkerend the population is racially and culturally diverse, with concurrent challenges facing the team in overcoming linguistic and cultural barriers imposed by the local situation. It is against this background that the current evaluation was undertaken.

AIMS/ OBJECTIVES:

The aim was to investigate factors operating at the health care professional/ child/ carer interface that could affect the efficiency and effectiveness of the BPHSP service being offered in order to make any recommendations for positive changes in service provision. Within this context, the following issues would be considered:

Parental/carer's perspective:

- To investigate parents' perceptions of services being offered and their appropriateness.
- To identify any gaps in communication and explore parental views regarding potential measures for overcoming these barriers.
- To ascertain the level of awareness of parents/ carers of children identified with special care needs regarding other local Sure Start Services and to determine any barriers to access.
- To assess parental experiences regarding the added advantage of Sure Start services.

Health care professional's perspective:

- To examine health professionals' views regarding the added advantage of Sure Start physiotherapy services for these groups.
- To investigate perceptions of local primary health care providers regarding identification of special needs, including current referral mechanisms available to facilitate access to specialist services.
- To enquire into issues around communication and understanding
- To identify best practices in order to inform the service planning processes.

METHODOLOGY:

Exploratory work was initially undertaken by a bilingual Research Fellow (AM). She accompanied health visitors, midwives, physiotherapists and physiotherapy assistants in order to gain a greater insight into those factors that might influence BPHSP service provision, that would require further consideration when constructing an interview schedule for the subsequent interviews.

Initial work indicated the need to consider various perspectives across a range of stakeholders including parents/ carers, physiotherapists and physiotherapy assistants. A qualitative approach was adopted in order to assess the various perspectives in depth. Permission to undertake the study was obtained from the Bradford Local Research Ethics Committee.

Different perspectives were gathered by conducting three focus groups as follows:

1. Physiotherapists - mainstream (N=12): the group was organized by Sure Start's senior physiotherapist.
2. Physiotherapy assistants (N=3), two with experience and one volunteer. The session was organized by the Health Lead in Sure Start.
3. Parents with a child who had used the BPHSP. All parents were contacted by the physiotherapy team and requested to participate. Initially it was planned to involve 15 participants in focus group work. Ultimately, three attended a focus group and a further four were accessed through home visits on a one-to-one basis. It was a convenience sample.

A detailed schedule of questions used among the various groups is shown in Appendix 1. Participants were given information about the research (Appendix 2) and written consent sought (Appendix 3) prior to participation. Where families were not available to leave the house to attend focus groups, domiciliary visits ensured access to them on a one-to-one basis.

Group and one-to-one discussions were audio recorded. Conversations were transcribed in order to organize findings thematically. Common responses to questions were identified from the data as well as broader themes at a more conceptual level (share ideas and meanings). Grounded theory was used to extract respondents' understanding of children's special care needs and their respective roles in the development of young children. Once the results were compiled, the ultimate aim was to develop agreed models of good practice with stakeholders in order to inform the service planning process.

FINDINGS:

Introduction:

The views of health professionals and physiotherapy assistants were successfully elicited regarding various aspects of service provision. The organisation of meetings with parents were more challenging. Unfortunately, only three participated in focus group work and another four were seen in their homes on an individual basis. The focus group was comprised of three 2nd generation mothers of Pakistani origin and the mode of communication was Punjabi and English. The individual domiciliary visits involved three Pakistani (two 2nd generation and one 1st generation) and one Bangladeshi mother (1st generation).

The findings have revealed a wealth of data. These have been collated and presented under various themes. Initially, the results of discussions with the parents are presented in relation to their observations on the benefits of Sure Start and, since they have children with special care needs, in relation to barriers to accessing services, as well as their knowledge and experiences of aspects of the BPHVS together with comparison with the equivalent hospital services. Subsequently, the perspectives of the health professionals are presented.

Mother's/ Carer's Perspectives

Sure Start:

Since all parents participating in the survey had a child who had used the BPHSP, their knowledge about general aspects of the Barkerend Sure Start Programme proved fairly high. Sure Start was perceived as beneficial in terms of providing information, help and a variety of appropriate services for children in general, for children less than four years of age in particular, for parents and for the whole community. Among the various activities mentioned was the Sure Start summer programme, including 'family fun days' and 'play sessions for children' as well as the various courses for women (e.g. computers, first aid, baby massage). Nevertheless, while there appeared to be plenty of activities for women, concern was expressed about lack of provision of corresponding services for local men.

Since its inception, Barkerend Sure Start has developed a range of new, more accessible activities, where South Asian women in particular can feel comfortable to participate. Womenzone is the new women's centre, designed to cater exclusively for the needs of women. The secure provision for learning and social facilities offered there was highly appreciated and valued for its management by women for women. Mothers could get together and their children could play together in an environment that felt safe.

- *'It provides a chance for mothers who are not allowed out or can not come out.'* *'Because of our religion we can't really talk with men (outside the family) so it gives us the chance to get together with other women and your husband knows that you are just with other women.'*

One mother, who had heard the positive publicity but not yet participated in any way, found the idea appealing. Apart from direct benefits for the health and welfare of the child, mothers also identified benefits for themselves in as much as it brings them outside their *chardiwari* (4 walls of the house) to participate in a range of activities being offered by Sure Start.

Sure Start was valued in terms of looking after the particular requirements of children with special care needs. However, partly because of their domestic duties, mothers felt that it was not always possible to make full use of services offered due to competing priorities and limitations. One mother mentioned that she had been asked to join a traineeship course for speech therapy, leading to a degree level course, but would consider this option when her children were older. Another stated that her life was 'too hectic' to join playgroup sessions, while bringing up three children in overcrowded accommodation (a two-bedroomed back-to-back house).

The Physiotherapy Home Visiting Service (BPHVS):

Knowledge of the service's function:

When asked about their perceptions of the physiotherapy home service, most parents related it to their own personal experiences which confirmed that they understood the broad principles:

- *'Physiotherapy exercises are designed to improve my daughter's mobility.'*
- *'It is designed to help anyone with developmental delays'*
- *'It is for children that can't walk'*
- *'It is for muscle weakness'*
- *'It helps special needs children - children that can't walk.'*

Experience of being introduced to physiotherapy services:

The process leading up to the diagnosis of 'special needs' together with the series of meetings with health professionals to address those needs can be a very daunting experience for parents and guardians. When asked about their experiences, the response was:

- *'The first time they tell you, you worry. What is wrong and how is it going to work out?'*

- ...' *One is always worried about the unknown. New people, new needs. What are the long-term effects of the condition? Who are they and what will they do to my child?*'

However, parents confirmed that the physiotherapy service had been able to allay their concerns:

- *'I am very happy with the service as it helps me to relieve my chinta (worry) I always worry more when I am on my own and talking to the Physiotherapy assistants is very helpful.'*
- *'I think mentally I am hyper because I really worry about him. I used to be really sad, why is he like this? When other children are walking, why isn't he? But I'm really happier now.'*

Perceptions of the value of the physiotherapy home-visiting service:

Parents confirmed that most of them received adequate information at the onset of the treatment:

- *'Yes, they did tell us that they were going to come round because in the beginning they used to come round every week, every two weeks. They said it was for the special needs of our child and gave us all the details.'*
- *'My daughter has developmental delay and she is doing much better with the physiotherapy. They are helping her a lot. She can crawl and can go around furniture and everything. She hasn't got the confidence to walk yet.'*
- *'L... 's progress is much better since their intervention. She is much livelier and bright. She has come on leaps and bounds since the start of Physio. It is helping to firm up her muscles.'*

Language Issues:

Language may present problems, especially for hard-to-reach components of the community. For instance, those languages offered by the bilingual assistants may not coincide with the first language of the parent. The extent to which comprehension is compromised by working in a second language is hard to assess. When the Bangladeshi mother was asked to explain whether she had any communication problems when dealing with the physiotherapy home visiting team she said:

'During Physiotherapy visits my husband is always present so he can talk to them in English. S... the Physiotherapy assistant speaks Urdu very slowly and I can understand her OK.'

Added value of the Physiotherapy Home Visiting Service:

The physiotherapy home service also provided the opportunity to offer other forms of support - advice on transport issues, housing advice and help with completion of the Disability Living Benefit forms. The non-English speaking mothers were less aware of such services.

Requests for further development of the BPHVS:

While the home visiting service was highly valued, more frequent visits were requested. At the same time, any cancellations by the BPHVS tended to heighten their anxiety.

- *'I would like a physio to visit every week at home.'*
- *'Sometimes they cancel it, not every time but quite frequently and I do not like that.'*

Families with children with special care needs have additional burdens in terms of fulfilling their childcare and carer responsibilities. As a result, there were requests to extend the home visiting service to include other programmes, such as speech therapy and early learning portage.

- *'My child's not speaking at all. He needs speech therapy.'*

However, since speech therapy was already available in the area as part of the Sure Start service provision, parents were asked to explain why they were unable to access that service. One mother acknowledged that she was aware of this provision but that access was an issue:

- *'I think it is nowhere near enough. Also it will be better if they came out to our homes because some people can't go out as they have got other small children.'*

A parent was also disappointed that the Sure Start physiotherapy service provision ceased when the child reached their 4th birthday and wondered who would be there to help him after that.

Hospital vs. Sure Start approach to Physiotherapy Provision:

When asked to compare the hospital-based service which is 3-4 miles away with the home-based service provision, the majority of the parents and in particular the non-English speakers, opted for the latter. However, a few parents had no preference and although less accessible, the hospital based service was appreciated for its specialist advice:

- *'I prefer the home service because of childcare responsibility for a younger daughter who is 9 months old'*
- *'Sure Start is better as they are more homely, friendly and down-to-earth'*
- *'I can't say much though as I mainly get the help from Sure Start and have only been to CDC (Child Development Centre) once. Sure Start is more convenient as I don't have to carry nappies and bottles with me.'*
- *'I appreciate both services and they are equally good.'*
- *'The doctors make sure the activities are working well. He will check to see what was done and what good it has done to the child, whether he is improving or not. BUT he won't do the activities like T (physiotherapist) does.'*

The health professionals' perspectives

Physiotherapists and physiotherapy assistants were consulted to provide their views and perceptions regarding service delivery and the challenges encountered.

Added advantage of Sure Start BHVPS.

Mainstream physiotherapists confirmed that once they receive a referral, they are normally able to see the child at the Hospital within three weeks. Any delay in the system occurs before the child is referred to them. Nevertheless, they identified 'the home-based approach' of the physiotherapy home visiting service within the Sure Start Programme to be its strength.

- *'With Sure Start there is a meeting up with parents and children with physical conditions in the locality and I think that is good for the parents. The benefit is the locality base. They can walk there, they don't have to get the bus, don't have to get a taxi and that is often a barrier to coming here because they have got to get on a bus. Although we may provide transport, it's much more accessible for them in the locality.'*

The additional use of bilingual physiotherapy assistants were associated with the programme's ability to provide a more user-friendly service, which goes beyond the realm of the mainstream physiotherapy provision:

- *'I work in the area and work with the children and quite a lot of parents say how good it was to have people coming to their home.'*
- *'If you have got someone regularly coming into your own home, you have got more of an idea of "this is what I'm supposed to do" or you can check your technique regularly.'*

- *'They say that if they have a regular physiotherapist coming at home it would be better than attending CDC. They have not realised that it is a spin off. They feel confident that professionals can come and explain personally. With home visits there are other benefits, which are unrelated to physio. Working in the community there is an increased confidence because they are not just getting the physio but they're getting the whole Sure Start package.'*

The majority opinion on using home-based physiotherapy assistants was positive. However, one member of the group thought that it could be a disadvantage as the Sure Start approach may disempower parents. It could mean families fail to do their own share of work on their children and leave sole responsibility to the home visiting team:

- *'I think that children in Sure Start will get more input and much earlier than they would in the CDC..... I just wonder how assistants going regularly in Sure Start may disempower parents as they may be thinking 'well isn't the physiotherapist or assistant coming to do my child's physiotherapy?' or 'it's the assistants' role', and maybe they won't take on as much responsibility as we'd expect them to do here.'*

There was disappointment with the rate of missed appointments in mainstream provision. A number of theories were proposed to explain the 'did not attend' (DNA) cases. Lack of understanding has been blamed for non-compliance. A debate evolved around various strategies required to improve service uptake. The majority opinion remained in favour of a home-based approach.

- *'A lot of people, through lack of education, don't understand the concept of physiotherapy. We get a lot of DNA or missing appointments because people just don't understand. If you explain to them on their own ground, in their home, they then can take on board exactly what's expected of them because they do play such a big part in the development of their child. So regardless of whether it's a weekly or 3-weekly input, the take up is much better with Sure Start.'*
- *'I feel that the push is towards the community anyway and we need to meet people where they are and that is what people want as well.'*
- *'I think the home based approach is much more effective. People are more receptive in their own home or in a home environment than when coming to a hospital. There are some cultural barriers as well and reaching out to them makes the service much more acceptable.'*

There was an element of frustration that mainstream services might not be best placed to promote continuing care, coupled with the level of parental understanding of the role of physiotherapy services for

children with special care needs. There were issues around understanding the need for the appointment, lack of time to provide explanations, inflexible hours, people changing addresses. Sure Start services were seen to provide advantages in terms of greater choice of appointment times and language support. In general times, solutions ranged from providing early support, helping families to understanding the need for the appointment and getting them to be partners in sharing concerns for the child's welfare.

- *'Early support is essential. If they can get support very early, then it helps them to have a more positive attitude towards the child and towards the intervention. The whole family is better equipped to deal with the problem and this has a better long-term effect. It also makes them realise that the physiotherapists are not from another planet.'*
- *'Well it depends on the parents. They have to understand the reasons for coming to us. If they understand and they have their own concerns then they will make every effort to attend. Otherwise there are excuses such as illness or the car broke down.'*
- *'They usually have no idea why they are coming. We do not have enough time but it would be better if someone was available to explain it to them. We don't have enough resources.'*
- *'I think it is because we are not very flexible. We only work on certain days and people do not have much choice. I believe with Sure Start they are given the choice of morning or afternoon session and also a choice about specific time but we can't do that.'*

Overall, there was concern about the families' lack of awareness of services or of a need for these services. Also, the changing ethos of providing patient-orientated health care services could present additional challenges.

- *'Everything revolved around the appointment model, you have an appointment with your doctor,.....But now everything is changed. It is the professionals who go and see them and therefore they want us to go to them a lot more than they ever used to.....'*
- *'I had a negative experience with one family. They were certainly not concerned about the state of their child. When I went to visit them at home they had no idea that I was supposed to be going to them. Perhaps it is better that they should feel the need for the treatment - so that when they have an appointment they can bring the child to the clinic.'*
- *'It is their attitude!'*

The mainstream physiotherapy services have a district-wide workload, with very limited capacity to offer home visits. The Sure Start service is locally based and offers families choices:

- *'Well it is much easier for them as they (Sure Start Physiotherapists) only have to consider the kids in one area only and not from all over the place, like with us.'* (Physiotherapists from CDC).

Language issues:

Physiotherapy assistants were asked to comment on potential communication problems, especially in the context of non-English speakers:

- *'... most of them can speak Urdu. Or you try to speak as clearly and as little as possible and you don't go into too great detail as to what you are trying to do or what you are trying to explain to them. I try to explain in as small a sentence as possible, but you do try to explain the whole thing. Because like you say we've got a very diverse workload, some Bengalis, some Gujaratis, but most of these can speak English as well. The young Mums are from here (the UK), but the ones that can't (speak English); you can still get through to them, with a bit of Urdu. So I can say that we can get through to all our families.'*

As both of the Physiotherapy assistants were Punjabi and Urdu speakers, they were asked about the need for additional personnel to cater for other community languages. One of them, who had been working in the programme for two years, explained that she had not come across any communication problems with her families. Her concern was that if they did recruit a Bengali or Gujarati speaker, that person might not be able to speak in Urdu or Punjabi. Overall, the Physiotherapy Assistants appeared confident of their skills to reach out at a universal level, but problems with recruitment were blamed for gaps in the service. Apparently it is difficult to recruit South Asian, with the necessary language skills to their posts and there have been few applications. The importance of physiotherapy assistants as key agents in meeting communication needs was re-emphasised during further discussions with the mainstream physiotherapists.

Mainstream physiotherapists admitted that they are faced with challenges when dealing with non-English speaking users. There is indeed a severe shortage of physiotherapists with the appropriate language skills:

- *'Well I know a few basic, basic Urdu words. They are certainly not enough to get any useful info but the child himself may speak English so we can always talk to the child and that will certainly ease the situation we can ask them to sit or lie down but the info and concerns we need to access directly from mum. So we urgently need more assistants who can be available to accompany us.'*

- *'Although we have a number of very good assistants they have their own problems. is leaving us because her husband does not want her to work and some might have child care problems.'*
- *'Another problem is that we have not had any great uptake from the Asian community and there is some lack of interest in physiotherapy assistants' recruitment.'*
- *'There are a lot of special needs assistants in Barkerend School who would love to apply for this post but they never get to hear about it. They would be ideal. They already work with children. They know what special needs are and they have the experience too.'*

Communication Strategies:

Physiotherapists mentioned the use of a variety of icebreakers to pacify parents on their first contact with them. They appreciate that it could be quite scary to have someone in your house, so it is very important to make them feel relaxed. Where possible, the introduction would include a few words in Urdu (*aap ka naam kia hai?*(What is your name?) or *mera naam C. hai* (my name is C).

- *'I always describe what the child has and also what I am going to do to him. I also give them a chance to ask me questions and express any concerns that they may have. There is no set way of going about it. It all depends on the needs of the child and the parent.'*

Barriers to the provision of home care:

A home-based visit means that other members of the family may be present during the therapy. They may not understand the programme objectives and do not wish to see the child disturbed in any way. The 'granny phenomenon' can be explained by the following comment arising from the experiences of one of the physiotherapy assistants in dealing with other members of the extended family who might be present at the time of their home visit:

- *'... you have to do the exercise with the child. Sometimes the child will cry. What we try to do is be friendly with the child; once the child has got to know us we do all the exercises. This little child does not want to know you, full stop. He will not go to anybody, he will not do anything. So you have got to sometimes leave him on his mums lap, but when we do his exercise he cries a little and Grandma seeing him cry which makes her upset and she wants us to stop. Picks him up. But we are doing our work.'*
- *'We just don't give up. Grandma now says come in, she'll talk, but it's just that when you go towards her grandson, she is a bit, you know... But I think the child would get used to us because the child goes to a playgroup so he is in with other children. He is all right with their staff but when we are going (into the home), grandma is all picking him up and taking him away from us.'*

Over time, familiarisation with the child in the nursery environment could be expected to relax the child and is further hoped, with patience, to appease the fear of the extended members of the family.

Opinion of attitudes of professionals regarding special needs:

A community paediatrician based in the Sure Start area, described the attitudes of local GPs and PCTs in meeting the needs of children with special care needs. As founder member of the Barkerend Sure Start Management Team, she contended that the physiotherapy home visiting through Sure Start had led to earlier identification of needs. In addition, more time spent with a health professional during a home visit had already contributed to several useful 'spin offs' including the diagnosis of a perforated eardrum for one of the mothers.

The community paediatrician maintained that some local general practitioners were not very active in identifying and referring special needs cases. Unfortunately, recently changes in health visiting regulations meant that health visitors had less time for their routine visits and hence possibly missed the early identification of some special needs children. PCTs and local GP's needed to appreciate the merits of this service and pave the way for its eventual mainstreaming. Due to time constraints on the part of the researchers, health visitors and local GP's could not be approached to verify these claims.

Current Referral Mechanisms:

An enquiry was made about sources of referral. For mainstream physiotherapists, referral mechanisms are via the GP:

- *'We are in secondary care so we would not know anything about it unless the GP..... gets in touch with us.. (e.g. whether an anxious mum contacts the GP, or the GP contacts the CDC).'*
- *'We can only accept referrals from within the CDC. If the parent is concerned, we normally ask them to go to their GP first. We can't accept referrals from parents.'*

Once they have a referral, children are usually seen within about three weeks. However, the mainstream physiotherapists did confirm that some parents had told them that they felt they were 'fobbed off', having to go back to their GP three or four times to explain that there is a problem and they want something done before anything was done. The physiotherapists then do their best to reassure them. However, there appear to be constraints to the referral system out with the physiotherapy service, which may be a cause of delay (as identified by the community paediatrician).

Summary of Best Practices:

Table 1 outlines the best practices associated with the physiotherapy home visiting service in the light of the prevailing local needs and Sure Start Barkerend’s current capability to meet those needs. For example, users’ lack of confidence and childcare and carer status are being addressed by having a user friendly flexi service which is arranged to suit the clients’ convenience. Similarly, there are telephone reminders of appointments and mothers are given the chance to ask questions and request information in their mother tongue.

Table 1: User Needs/ Strengths offered by the Barkerend Sure Start Teams, identified by focus group and one-to-one interviews.

User Needs	Strengths of Sure Start
Worry, concern, lack of confidence	User friendly approach
Physiotherapy a new concept	Appropriate health education
Quicker referral mechanism locally	Health visitors, GPs, community paediatrician, directly to the BHVPS
Competing priorities including other children	Local home based service, flexible
Potential problems: Language	Bilingual assistants, from within the community
Locations	Locally based
Lack of diary keeping skills	Reminders
Granny phenomenon	Family orientated approach aimed at appeasing fears
Additional unexpressed needs	Needs identified and supported

DISCUSSION:

This study involved a qualitative methodology using small numbers of participants in order to gain insights into the conduct of the BPHSP. In addition to the physiotherapists and the physiotherapy assistants, the original sample was designed to involve focus groups with 15 community-based participants, but this proved impossible to achieve. As in the local population, the majority of mothers finally interviewed were of Pakistani origin, plus one Bangladeshi mother. Interestingly, the Barkerend User Satisfaction Survey⁸ had identified two white families that had used this service together with one Pakistani parent with a special needs child.

A number of challenges affected the progress of the research. The study depended on meeting 'hard to reach' families, that is where there may be mothers with linguistic and cultural barriers, single parent families and a considerable burden of childcare responsibilities. The attempt to convene a focus group with 15 participants who had already given their verbal consent failed to materialise and only three mothers turned up for the event.

Two issues arose as a result of this experience. Firstly, the situation provided an additional challenge for the researcher and hence some of those non-attendees were subsequently interviewed on one-to-one basis in their homes. As a result of this difficulty, the month of Ramadan then intervened in the progress of the research, since no one was available to be interviewed. The individual interviews had to be postponed until after Eid ul Fitre (the festival at the end of the month of Ramadan). Secondly, the question arises as to 'typical' nature of this sample due to the non-response bias⁹, although the one-to-one home visits will have included 'hard-to-reach' families.

Transcription of all the interviews was time consuming and, by necessity, was carried out by the researcher. Factors such as the presence of children during the focus group discussion, individuals joining or leaving at their own convenience and more than one person talking at the same time can present serious problems for someone who was not present at the time of recording. Nevertheless, despite these challenges, a number of key themes have emerged.

When a child has special care needs, it is important that any disability be recognised as early as possible so that appropriate remedial programmes can be instigated to support the child and his/her family. Early identification and early intervention are key themes in the 2001 Special Educational Needs Codes of Practice (10). They are central to a number of government initiatives including Quality Protect and Sure Start, and they should form the basis of care provided by all the professionals. Effective early

intervention and support can produce improvements in children's health, social and cognitive development.

The measure can also help children with special needs and emotionally support the parents and hence improve outcomes for the whole family. In the present study, there is some evidence to suggest potential for delay in moving through the primary care referral system where GPs were involved at the identification stage, although once secondary referrals have been made, remediation is fairly prompt. The Barkerend User Satisfaction Survey⁸ also reported that 10% of local respondents were dissatisfied with GP services, which were 'rushed', involved extended delays in getting appointments plus two allegations of 'not checking properly'. The results of the present survey confirm that the provision of a community paediatrician in Barkerend Sure Start plus the revised referral systems has been perceived as a positive step in addressing referral delays.

Communication is a key issue. The process of informing parents about their child's special needs can have a profound effect on their view of the support services and their ultimate compliance or willingness to use them. Effective communication at this sensitive time is fundamental to avoiding a distressing situation and establishing a positive relationship between parents, professionals and the child. This study has confirmed that the bilingual physiotherapy assistants have helped to support this process.

From the user perspective, lack of perceived need for physiotherapy services may present a major barrier. Perceived need is a complex issue. It can incorporate lack of comprehension of special care needs, be related to the degree of impact of the disability within the context of daily living, or influenced by beneficial effects derived from the remedial procedures. Raising awareness at a conceptual level is a very challenging task and requires understanding of these key issues together with the characteristic features of the community being targeted. A prerequisite to a successful health promotion programme would need to take into account the definition of disability as perceived by these families together with their views on the credibility being given to the remedial effect of physiotherapy service.

Against a background of additional childcare needs, carer status, financial considerations and the remoteness of mainstream services, the value-added aspect of the Sure Start programme makes an important contribution. Although many barriers are common to all residents in this areas, it is the linguistic and cultural differences that contribute to the additional disadvantage suffered by South Asian communities. Evidence from this study points to the fact the non English speaking users feel more comfortable when approached at home than when invited to a clinic based setting.

Comparison of missed appointment figures collected from Sure Start Barkerend and CDC of 7.6% and 19% respectively, lends support to the success of this domiciliary approach. Analysis of the missed

appointment cases within Sure Start provision indicates that 72% had forgotten their appointments and were not available at the time of the planned home visit by the physiotherapist or the assistants.

Such findings fuel the debate on whether it was the lack of understanding about physiotherapy and the value of that service, lack of perceived need or more related to the diary keeping skill that accounted for the wasted time. Recent work carried out with the Pakistani community of Leeds indicated that lack of perceived need certainly had an impact on their access to dental services¹¹. Relative under-use of physiotherapy services was recorded in a national survey, where people from various minority ethnic groups were asked about attendance within the previous 12 months. A lower uptake of service was recorded among South Asians, with corresponding figures for Indian, Pakistanis and Bangladeshis being 5.8%, 3.9% and 0.6% respectively; whereas comparative figure for the White population was 9.0%¹².

Special needs and disabilities in childhood can place an extra strain on families and can have implications in terms of childcare responsibilities for the other children in the family. They may also require emotional support to cope with potential isolation and a sense of helplessness as well as how to deal with public ignorance related to the condition. They may need to find out about other services available to help with short-term break and housing adaptations. The results from this study indicate that although there is much appreciation of the physiotherapy home service by these users, the non-English speaking Asian families are not aware of any other support network. English speakers have acknowledged support with completing applications for Disability Living Allowance as well as help with adapting some of the facilities. All the service users approached here have praised the Sure Start physiotherapy service for its positive effect on their child's progress and also for easing their frustration and strain associated with their child's condition.

A workforce which is representative of the local community is more likely to be successful in delivering culturally appropriate services. This aspect features strongly in relation to Sure Start Barkerend and provides an added bonus compared to the mainstream service. Punjabi and Urdu speaking physiotherapy assistants are being used to assist with communication. Previous work with ethnic minorities shows that the largest group which is dependent on the interpreting services belongs to Bangladeshi women³. Therefore, consideration should be given to employing physiotherapy assistants or trained interpreters from this sector of the community.

The evidence collected from physiotherapists and physiotherapy assistants indicates that there are recruitment problems associate with the physiotherapy assistant's post. In the absence of a fully qualified therapist the assistants are an extremely valuable resource. Measures are required to improve their uptake and retention, possibly including a nationally recognised qualification which would improve their

transferable skills. Subsequent motivation and rewards would ensure their retention and also increase its career appeal for prospective candidates.

The recent cost-effectiveness analysis conducted at Barkerend¹³ calculated the physiotherapy home visiting service at £99 per visit, compared with £42 for home visits as costed by Netton & Curtis¹⁵. As was pointed out, there are important case mix difficulties in making comparisons between conventional physiotherapy and a paediatric service of the nature offered in Barkerend. Previous work has shown that the BPHVS is more efficient in terms of reducing missed appointments and the present study has demonstrated that the service is clearly valued by its users. Evidence for earlier referrals into the BPHVS, using historical controls, should also be collated, if possible. In order to balance these clear benefits against other service aspects of this work, it is recommended that an internal audit be conducted in order to determine whether physiotherapy functional outcomes are achieved more rapidly within the home setting compared with that obtained among a similar cultural/ linguistic group attending mainstream secondary services. Consideration of the relative duration of visits and the opportunity costs for the family and for the provider would also need to be taken into account. These results would then help to provide a balanced approach to inform judgment regarding mainstreaming this type of service.

The present study has confirmed that, in the context of the Barkerend Sure Start Physiotherapy Home Visiting Service, the programme is building social capital, empowering mothers and providing emotional support in culturally appropriate ways and in areas where they were not previously available.

CONCLUSION:

The study investigated factors operating at the health care professional/ child/ carer interface that could affect the efficiency and effectiveness of the BPHSP service being offered through the Sure Start programme. A qualitative methodology was used in order to explore in-depth the views of health professionals and of local South Asian mothers.

Parents who have children with special care needs generally appreciated the home-based service being offered, the access to bilingual workers and the quality of the explanations and the care available. Additional advantages of this home-based service included identification and support in relation to other family needs. Many mothers preferred the local, friendly, physiotherapy service provided through Sure Start compared with the mainstream provision because it was convenient and saved time.

The health professionals and physiotherapy assistants generally agreed that the locally-based service had distinct advantages for families, although there was concern that some parents did not understand or value the service sufficiently. Disquiet was expressed about delays in referring into the mainstream physiotherapy service through the former GP-based primary to secondary care route - which was now being by-passed in Barkerend through the wider-access Sure Start arrangements. The lower DNA rates incurred through home visits compared with the mainstream services were seen as a definite efficiency gain.

Cultural and linguistic barriers were thought to be a potential source of difficulty for some families in understanding and being able to take full advantage of the service, with a need for health education in order to raise awareness in local South Asian communities. The work of the bilingual physiotherapy assistants was highly valued but since recruitment appeared to be problematic, this issue needed to be urgently addressed. Recommendations have been developed to inform changes in service delivery and any accompanied health promotion programmes.

RECOMMENDATIONS

1. There is a continuing requirement to ensure early recognition of special care needs at primary care level, accompanied by a fast track referral mechanism to specialist services.
2. Further recruitment of physiotherapy assistants from within those communities being targeted should be actively encouraged.
3. Appropriate measures are needed to advocate for nationally recognised training programmes to attract physiotherapy assistants. Subsequent encouragement and rewards should be designed to ensure their retention on the programme.
4. Similarly, recruitment for physiotherapists from these communities should be facilitated.
5. The findings of this project have confirmed a need to continue patient support and empowerment programmes.
6. In order to bridge the gaps in diary keeping skills of users, more frequent telephone reminders could precede any home visits by the service providers.
7. There is a need to review whether home-based services should be provided for other key developmental programmes, particularly for families with special care needs.
8. Consideration should be given to requests from the community to extend home-based physiotherapy provision beyond 4 years of age for children with disabilities
9. Any future health promotion programmes should take into account the religious, cultural and linguistic needs of the community. As disability affects everyone in the family, siblings and members of the extended family should be involved. Community based health promotion programmes ought to be conducted in their mother tongue.
10. There is a need to raise awareness of all stakeholders, especially health professionals, regarding cultural and linguistic barriers which could hinder access of children and their parents to key remediation services.
11. The Sure Start model has proved very successful in a number of key aspects. Subject to some additional internal auditing checks of home-visiting physiotherapy outcomes and activity, consideration should be made to extend its philosophy and practice into mainstream provision.

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APPENDICES:

APPENDIX 1

APPENDIX 1 (a): Focus Group Guide for Parents/ Guardians:

General Awareness of Sure Start:

- ✓ Have you heard of Sure Start before this session?
- ✓ Do you know what Sure Start does in your area?
- ✓ Who is it designed to help and support?
- ✓ What are the benefits of Sure Start?
- ✓ Do you know of any activities planned through your local Sure Start?
- ✓ Have you been invited to join Sure Start?
- ✓ In what capacity?
- ✓ If yes, did you any concerns?

General Awareness of the physiotherapy services:

- ✓ Do you know who the physiotherapy service is designed to help?
- ✓ Have you had contact with them on behalf of yourself, friends or family? (check hospital service/home service, check for each on whose behalf)

General Awareness of the home physiotherapy services:

- ✓ How do they contact you? (eg to arrange visits)
- ✓ Is this the best way to contact you?
- ✓ If no can you suggest other ways?
- ✓ Do you get another appointment after each visit?
- ✓ Is it clear when the next appointment is?
- ✓ Have you ever missed any home/local physiotherapy appointments provided by the Sure Start Barkerend team?
 - If yes, how many times?
 - What were the reasons?
- ✓ How do you think your child may benefit from the service?
- ✓ If yes, how will they benefit/how have they benefited?
- ✓ Do you think there might be any benefits for the family as a whole?
 - If so what could they be?

Service Use:

- ✓ Does the physiotherapist give instructions that are easy to follow?
 - If yes, have they helped to improve your involvement with your child?
- ✓ Apart from the Sure Start team, has any one else approached you regarding special needs of your child? If yes, who was it?
- ✓ Do you communicate through health care support workers?
 - If yes, are you happy with this service?
 - If not, what are the concerns?
- ✓ Have you ever consulted the team about anything else regarding the welfare of the child?
 - If yes, what was it about?
- ✓ Have you ever consulted the team for any thing that is not related with the special needs of your child?
 - If yes, what was that about?

Communication:

- ✓ Has any one explained to you the purpose of the physiotherapist home service?
 - If yes, who explained it?

- Was it in verbal or written form?
- ✓ Do you need anyone to help you communicate with the health professionals?
 - If yes, who helps you?
- ✓ Can your child understand the instruction given by physiotherapy team?
 - If not, how do they manage?
- ✓ Prior to starting the physiotherapy did any one ask your permission to see whether you would like to be part of this programme?
 - If yes, did you have any worries?
- ✓ In order to make the service better would you like me to explain any points to the service providers?

Those with experience of home physiotherapy services AND hospital physiotherapy services:

- ✓ In comparing the two services, please tell me which one you prefer and why?
- ✓ Does going to the hospital mean you get a better service?
- ✓ If you go to hospital, how much of your time does it take from home to back home?
- ✓ So what would a hospital visit for your child with special needs involve for you, compared to a home visit (e.g. time, transport, cost, child care)

Thank you very much for your giving me your time and help.

APPENDIX 1 (b) Focus Group Guide for physiotherapists (Sure Start and mainstream):

General:

- ✓ Do you think that the physiotherapy home service is an important part of the Sure Start programme?
 - If yes, please explain why?
- ✓ How does the Sure Start home visiting service compare with the mainstream service and fit alongside it? (personal work experiences, workload, job satisfaction, networks, support)

Physiotherapy Home Service:

- ✓ What are the perceived benefits of home service for the users?
- ✓ Can you identify any evidence of such benefits from your personal experience?
- ✓ Where do you obtain your referrals?
- ✓ What is the time lag between referrals and therapy provision in the mainstream system?
- ✓ What is the time lag between referrals and therapy provision in the Sure Start system?
- ✓ Have the parents/guardians ever missed any appointments?
 - If yes, how many times?
 - What were the reasons?

Communication:

- ✓ How do you approach parents for the first visit?
- ✓ Do you obtain parents/ guardians' consent?
 - If yes, in what form is it?
- ✓ Are there any special communication issues when dealing with the users?
 - Special needs, that of parents/guardians'?
 - Linguistic needs?
 - How are they overcome?
 - Are you satisfied with these measures
 - If not, would you suggest any improvements?
- ✓ Are you satisfied with the communication and therapy provision by the bilingual assistants?
 - If not, are there any concerns?
- ✓ Are there any special communication issues when dealing with other professionals?
 - What is the source of referrals?
 - Do you ever make any referrals to some other agency?
 - If yes, please specify.
- ✓ Are there any refusals and non-responses?
 - If yes, how are they tackled?
- ✓ What is the refusal rate?
- ✓ Can you describe the setting?
- ✓ Are there any distractions (*family members, visitors, TV etc.*)?
- ✓ Do you involve anyone else in the physiotherapy treatment as well?
 - If yes, how?
- ✓ How do you process your findings?
 - (internal recording, info sharing with other professionals, who are they? Explore their relationship with other agencies?*
 - How often do they exchange info?*
 - Is there any special format for reporting?*
 - Do they share their findings with mainstream therapists?)*
- ✓ Have the parents or guardians ever sought your advice for anything unrelated with the welfare of their child?
 - If yes, what was it about?
 - (Without jeopardising the confidentiality of the individuals ask them to elaborate the nature of the advice given).*

- ✓ Are there any regular attempts to internally evaluate the physiotherapist home visiting service and who contributes to the process?
 - If yes, who normally contributes to it?
 - What is the outcome of the findings?
- ✓ Can you make any suggestions that may improve the service?

Thank you very much for your time and help.

APPENDIX 1 (c) Interview guide for Physiotherapy Assistants:

General:

- ✓ Who employs you?
- ✓ Can you highlight any benefits for the community using the Sure Start home physiotherapy service Barkerend?

Home physiotherapy scheme:

- ✓ How long have you been involved in the Sure Start programme?
- ✓ What is your role in physiotherapy home visiting programme?
- ✓ Do think the physiotherapy Home Service is useful for children with special needs and their families?
- ✓ Do you ever accompany physiotherapists on home visits?
 - If yes, what are your responsibilities during these visits?
- ✓ What special training have you received for the physiotherapy Home Service?
- ✓ In this context, do you need any further training?
 - Please specify
- ✓ Sure Start Barkerend has families that are culturally diverse, how do you communicate with all families within this area?
- ✓ What are the distractions in the home setting?
 - How do you deal with them?
- ✓ Have the parents/guardians ever missed any appointment?
 - If yes, how many times?
 - What were the reasons?
- ✓ What are the difficulties experienced during translation?
- ✓ Can you make any suggestions for parents/guardians to help them improve their participation in the programme?
- ✓ In order to improve the service, do you have any suggestions for the physiotherapists or families?

Thank you very much for your excellent cooperation and a valuable insight.

APPENDIX 2 (a) Information Sheet Parents/Guardians:

Invitation to join the study:

We are asking you to take part in a study that aims to give us a better understanding of what services are available for babies, young children and their families in your area. We would like to know if there are any barriers to using these services and whether there are any recommendations we can pass on. Please take time to read the following information carefully, and decide whether or not you wish to take part. However, if there is anything that is not clear, or if you would like more information, please do not hesitate to contact us (contact details are given at the end of this information sheet). Thank you for taking time to read about this.

What is the purpose of the study?

The purpose of this study is to understand more about the physiotherapy services provided for children that you currently use in your area. We would like feedback on the services used so we can discuss your comments with Sure Start Barkerend so that they can tailor this service to better suit your needs.

Why have I been chosen?

You have been chosen because you live in one of the study sites and are the parent/guardian of a child who has used the physiotherapy service within Sure Start Barkerend.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. This will not affect your legal rights in any way or the level of care you receive from any service.

What will happen to me if I take part?

If you agree to take part, we will ask you to attend a focus group. This will be with other parents/guardians from the local area and we will discuss the types of services you have accessed on behalf of your child.

Are there any risks in taking part?

There are no risks associated with taking part in this focus group as it involves questions only.

What are the possible benefits of taking part?

There is no direct benefit to you or child. However, we hope that our study will lead to a better understanding of the Home Visiting Service provided by Sure Start Barkerend. We would then be able to see the difficulties you may have accessing them and gaps that may exist.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the office will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

The study is being funded by the Sure Start Unit, Bradford.

For further information please contact:

Mrs. Abida Malik

Research Fellow

Leeds Dental Institute

University of Leeds

Clarendon Road, Leeds LS2 9LU

Tel: 0113 2336181/ 0113 2336197

Thank you for taking the time to read this.

APPENDIX 2 (b) - Invitation and Information for Health Professionals/ Health Care Support Workers:

As part of evaluation of Sure start activities a research team from University of Leeds is trying to find out whether local services designed to meet the needs of babies, young children and their families are adequately serving their purpose. If you are involved in any way with the special needs of children whether at the recognition stage or during provision of remediation therapy, I would like to hear your views regarding the service delivery and any concerns that you may have from the users of the service or their families. Although the data collected will remain anonymous, it will help to identify any changes, which might be required to enhance the quality of the service or indeed to recognise good practices.

You are cordially invited to take part in a focus group where you will be provided with refreshments and also given a chance to enquire about our role Sure Start and physiotherapy programme.

Mrs. Abida Malik
Research Fellow
Leeds dental Institute
University of Leeds
Clarendon Way, Leeds LS2 9LU

Tel: 0113 2336181 / 0113 2336197

Email: a.malik@leeds.ac.uk

APPENDIX 3 (a) - **Consent Form for Parents/ Guardians:**

Name of Researcher: Mrs. Abida Malik

Please tick boxes

1. I confirm that I understand the information, which has been given to me and have had the opportunity to ask questions. []
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason []
3. I agree that my contact details can be shared within the research team for the purposes of this project alone []
4. I agree that I can be contacted for any further information about the discussion regarding Physiotherapy Home Service by the above named researchers. []

_____	_____	_____
Name of Person	Date	Signature
_____	_____	_____
Researcher	Date	Signature

<p>Contact details:</p> <p>Home address:</p> <p>_____</p> <p>Home telephone number/mobile telephone: _____</p>

Thank you very much for your help.

APPENDIX 3 (b) - Consent Form for Health Care Professionals:

Name of Researcher: Mrs. Abida Malik

Please tick boxes

- ✓ I confirm that I understand the information, which has been given to me and have had the opportunity to ask questions. []
- ✓ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason []
- ✓ I agree that my contact details can be shared within the research team for the purposes of this research alone []
- ✓ I agree that I can be contacted for any further information about the discussion regarding Physiotherapy Home Service by the above named researcher. []

_____	_____	_____
Name of Person	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Contact details:
Job Title:
Organisation: _____
Contact Details: _____
Telephone number/mobile telephone _____

Thank you very much for your help.

APPENDIX 4 (a) - Personal Data of Parents/ Guardians:

Personal details:

Name ID Code:

Date of birth ____ / ____ / 19 ____

Age ____

1. How many children do you have?.....
2. What are their ages?.....
.....
3. Are you registered with Sure Start Barkerend?.....
4. Does anyone in your home have special needs? No _2 Yes _1
 - if yes, please specify who?
 - how this affects’s daily life?
5. Who usually looks after your children during the day? (*Tick as many boxes that apply*)

Mother at home	<input type="checkbox"/> _1	Father at home	<input type="checkbox"/> _2
Sister/brother	<input type="checkbox"/> _3	Child’s grandparent	<input type="checkbox"/> _4
Other relative	<input type="checkbox"/> _5	Friend/neighbour	<input type="checkbox"/> _6
Paid child minder	<input type="checkbox"/> _7	Nursery school	<input type="checkbox"/> _8
Day nursery	<input type="checkbox"/> _9	Playgroup	<input type="checkbox"/> _10
Other	<input type="checkbox"/> _11	Please specify.....	
6. Who lives in your family home? (*Tick as many boxes that apply*)

Mother	<input type="checkbox"/> _1	Father	<input type="checkbox"/> _2
Mother and father	<input type="checkbox"/> _3	Mother and stepfather	<input type="checkbox"/> _4
Father and stepmother	<input type="checkbox"/> _5	Grandparents	<input type="checkbox"/> _6
Other relatives	<input type="checkbox"/> _7	Please specify	
Other	<input type="checkbox"/> _8	Please specify	
7. How many children are living in your house now?
8. What is your marital status?

Married	<input type="checkbox"/> _1	Single	<input type="checkbox"/> _2
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Divorced / separated? ₃

Widowed ₄

9. (i) What is your occupation?

9 (ii) What is the occupation of your spouse?

10. What is the postcode of your home address?

11. At what level did you finish your full-time education?

Primary school ₁ **Secondary school** ₂

Further education (college) ₃ **Higher education (university)** ₄

No formal education ₅ **Other** ₆

please specify

APPENDIX 4 (b)

Personal Data of Health related Staff:

Personal details:

Name **ID Code:**

Post with Relevant Grade:

Organisation/ Department:

1. How long have you worked in your present post?

2. How long have you been working with special needs?

3. What are your views regarding the usefulness of physiotherapy home service for:

(a) users

(b) service providers

4. Have you recently had any training regarding:

(a) Cultural and linguistic aspect (please specify):

(b) Any other esp. relating special needs (please specify):

5. Do you have any further training needs? Please specify.

6. Would you be willing to answer any specific questions regarding the service delivery?

If so, please provide your contact details as follows:

Name:

Post:

Address:

Work Tel:

Mobile `.....

Email: