

An Evaluation of Bobath Scotland's Adult Therapy Pilot Project

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Introduction

Ageing with Cerebral Palsy

The lives of adults with Cerebral Palsy have dramatically changed over the last twenty to thirty years, not least by the fact that their lives are now much longer¹. Before the 1950s, few people with CP survived to adulthood, now 65% to 90% of children with CP survive and have a normal or near normal life expectancy. Moreover the social and living arrangements for people with long term conditions have changed dramatically, the old long-stay hospitals have closed down and as a result of legislation and policy changes such as the Community Care and Health (Scotland) Act 2003 and more recently the Social Care (Self-directed Support) (Scotland) Act 2013 has meant that people with CP now expect to live in the community instead of institutions and to take part in the normal day to day activities associated with the mainstream of life. This has brought new needs and wants to mainstream service provision².

However, although long term conditions have become the central subject of reams of policy documents, CP has been conspicuous by its absence. This is partly because CP is traditionally viewed as a “static”, childhood condition and health and therapeutic services are based on this³. Most services for people with CP are found in the paediatric sector where the focus tends to be on habilitation rather than rehabilitation. When individuals with CP reach 18 years old the specialist services available for them to access quickly vanish⁴ and there is an absence of knowledge about their adult impairment-related needs among mainstream health and social care practitioners⁵. Services are organised around distinct “client groups” and so when disabled people are “in transition” from childhood to adulthood for example they can fall between the gaps both within and across services⁶.

¹ Jones, GC. (2009) Aging with cerebral palsy and other disabilities: personal reflections and recommendations, *Developmental Medicine & Child Neurology*, Vol. 51, Issue supplement s4, pp12–15.

² Zaffuto-Sforza, C. D. (2005) Aging with cerebral palsy, *Physical Medicine and Rehabilitation Clinics of North America*, Vol. 16, No. 1, pp235-49; see also Hemming, K., Hutton, J. L., Pharoah, P. (2006) Long-term survival for a cohort of adults with cerebral palsy *Developmental Medicine & Child Neurology*, 48, pp90-95.

³ Svien, L., Berg, P., Stephenson, C. (2008) Issues in Aging With Cerebral Palsy, *Topics in Geriatric Rehabilitation*, Vol. 24, Issue 1, pp26-40.

⁴ Jahnsen, R., Villien, L., Stanghelle J. K., Holm, I. (2002) Coping potential and disability – sense of coherence in adults with cerebral palsy in Norway compared with the general population, *Disability and Rehabilitation*, Vol. 24, No.10, pp511-518.

⁵ Svien, L., Berg, P., Stephenson, C. (2008) Issues in Aging With Cerebral Palsy, *Topics in Geriatric Rehabilitation*, Vol. 24, Issue 1, pp26-40.

⁶ Putnam, M. (2007a) *Aging and disability. Crossing network lines*, Springer, New York; Putnam, M. (2007b) *Moving from separate to crossing aging and disability networks*, in M. Putnam *Aging and disability. Crossing network lines*, Springer, New York; Bigby, C. (2002). *Aging with a lifelong disability: Challenges for the aged care and disability sectors*. *Journal of Intellectual and Developmental Disabilities*, 24(4), 231-241.

This is a particularly crucial absence facing adults with CP because we now know that growing up and growing older with the condition can bring about certain additional health problems. This is because whilst people with the CP age in the same way as non-disabled people (primary ageing), they can also experience accelerated secondary ageing due to the effects of living with a lifelong condition⁷. Primary ageing is the gradual and inescapable process of bodily deterioration that takes place throughout life and secondary ageing results from the impact of a disease or everyday bodily disuse or overuse. Thus lifelong musculoskeletal disuse or overuse by people with CP can mean that they can experience for example pain, osteoarthritis, muscle tightness, joint problems, urinary tract problems and fatigue in adulthood and old age.

Bobath Scotland recognised this problem largely through feedback from service users who had accessed their services as young people and were now looking for advice, help and therapy but had been unable to access any such support through the normal health channels. In trying to help their ex-clients Bobath Scotland developed a new service aimed at adults. They developed a short intervention programme and received funding for a two year pilot project from The Robertson Trust. The pilot was set up to offer up to 18 sessions of therapy to a number of adults with CP and to establish the magnitude and nature of the need for adult therapy with the intention of designing an ongoing service. Twenty-two adults took part in the pilot project and received therapy from Bobath Scotland.

The aim of this report is to provide an initial evaluation of what Bobath now call their Adult Therapy Pilot Project. This is a very tentative evaluation and given the very small number of service users and the diversity in their level of impairment and in the treatments offered to them quantitative measures were not taken and neither would they have been suitable for such an evaluation. This study adopted a qualitative approach to evaluate both the need for the service and the service users' views on the performance, outcomes and necessity of the adult therapy pilot project.

The Bobath Concept

The Bobath Concept provides a framework for understanding of the problems confronted by individuals with CP. The concept is based on a thorough analysis and understanding of the individual's problems that arise as a result of their impaired

⁷ Haak, P., Lenski, M., Cooley Hidecker, MJ., Li, M., Paneth, N. (2009) Cerebral palsy and aging, *Developmental Medicine & Child Neurology*, Vol. 51, pp 16–23; *Developmental Medicine & Child Neurology* (2009), Vol. 51, Issue supplement s4, pp1-184.

central nervous system and its impact on their sensory-motor, cognitive, perceptual, social and emotional development.

Bobath employs a framework for understating the major problems which confront individuals with CP. It takes an holistic approach to the body as it develops an understanding of how different muscles groups, senses, speech and hearing interact and works with the individual to develop strategies of coping to prevent the condition getting worst or at least stabilise it. It explores an individual's sensory-motor function, tone and patterns of movement and the way these affect the individual's ability to participate in everyday life. It relies on knowledge of how the clinical features evolve, and is proactive in working to minimise secondary problems.

Physiotherapists, occupational therapists and speech and language therapists can use this framework, together with specific handling techniques, to enable the individual to 'function more efficiently'. Education of the individual, their families and assistants, is an integral part of this approach, enabling "treatment" to be combined into everyday management. Bobath focuses on quality of movement rather than achieving function at any cost. Enabling a person to move or function may cause problems in the future – it is about sustainable functioning.

It is based on one to one treatment and therapists work with the individual to design individual, tailored treatment programmes which aim to enhance and develop new functional skills. All goals and outcomes are set in collaboration with the individual and their family.

Methodology

Research framework

The voices of adults with CP and their family were central to this evaluation. By placing their views and feelings at the centre of the research we were able to explore their perspectives on the adult therapy pilot project in relation to their lives and the extent to which they are receiving the necessary therapeutic support from both Bobath Scotland and elsewhere. These perspectives were contextualised with the views of Bobath Scotland therapists, allowing the personal experience of therapy service users to be set within the professional discourse and practice of the therapy practitioner.

Ethics/consent

Ethical approval was sought and gained from the School of Social and Political Science's Ethics Committee at the University of Glasgow. All research participants were provided with full information about the nature of the study and what taking part would involve. Informed consent was sought from all participants. Participants were told that they had the right to withdraw from the project at any time without giving a reason.

Recruitment and sample

Adults with CP

In total, 8 individuals taking part in the adult therapy pilot project were recruited and interviewed for the evaluation. Recruitment took place via a letter of invitation sent out by Bobath Scotland on the researcher's behalf. Participants' ages range from 20+ to 50+ years old and represent the diverse experiences of CP and the differing lives of adults with CP.

Bobath Therapists

A focus group was organised and conducted with 6 Bobath Scotland therapists at their Headquarters in Glasgow. The group included physiotherapists, occupational therapists and Speech & Language Therapists. One further therapist who did not attend offered written feedback.

Other professionals

In order to contextualise the views and opinions of both the service users and the Bobath therapists we have drawn on interviews we carried out with physiotherapists, Local Authority representatives and consultant adult neurologists across Scotland. These interviews have allowed us to situate the comments of the other groups and to also map out the range of services currently available to this group and their perceived needs.

Interviews

Interviews with adults with CP were semi-structured and took place at a place of their choosing. Broad themes were covered with each participant, but they were able to focus on those issues that they saw as the most important. Participants were encouraged to discuss their lives, their thoughts about the adult therapy project, and how they felt about the support they received from Bobath Scotland and mainstream service providers. A parent was present at a number of interviews to facilitate communication between interviewer and interviewee where necessary. They were sometimes keen to offer a parental perspective on Bobath Scotland and the adult therapy pilot project which presented additional data.

Focus Group

The focus group conducted with Bobath Scotland therapists was also semi-structured and was designed to be flexible. Therapists were asked about issues around growing up and growing older with CP and about the performance, outcomes and necessity of the adult therapy pilot project. Additional follow up questions were sent to therapists to reply in writing.

Analysis

Transcribed interviews and focus groups were analysed using a thematic approach⁸. Data was categorised into a series of themes and sub-themes identifying issues and topics of particular importance to participants.

⁸ Bryman, A. (2008) *Social Research Methods* Oxford: Oxford U.P

Findings

Physical changes associated with ageing:

One of the first questions we asked people with CP during the interviews was about how their health needs and their physical ability and functioning had changed and what it was that had made them contact Bobath looking for help in the first place. All those we spoke to expressed concerns about their changing health needs and how these were impacting on their ability to perform everyday activities:

... I think I found that as I got older I didn't have as much help physio-wise so I was getting a lot, lot stiffer and I was having challenges with things like getting in and out of bed, I would be quite stiff in the morning and I would have... I had quite a lot of back pain which was... Which I found quite worrying at the time...

Most participants described new musculoskeletal problems. They also all reported an absence of support from mainstream health and social care providers in relation to this.

The key problems adults reported included:

- pain and its physical and psycho-social effects;
- contractures;
- spasms;
- body maintenance issues;
- walking and balance issues;
- movement issues;
- functional and practical everyday task issues;
- posture and seating issues;
- strength issues;
- transferring issues;
- breathing issues
- orthotic issues.

People talked about how these changes affected their function but also, importantly how they had failed to get any help from their own general practitioner:

.....last year I felt that my walking... that I was struggling a bit and that I would be tripping quite a lot and that I had had a few falls and things and I was wondering how I could improve that. And through the normal Health Services all they could offer was very 'off the shelf' splint types of things and were thinking "We'll just put her in a corner..." type of thing. That was the way that I felt about it. It wasn't thinking about me as an individual and I felt that things didn't look too good at that point, if I am honest with you....

Pain was a key, overarching problem that all our informants described. This was a finding that was supported by the Bobath Scotland therapists who explained that the

major difference between adults with CP and children with CP is the experience of chronic pain and this was one of their key learning outcomes during the period of the pilot project. Children very rarely experience pain problems whereas the majority of adults who took part in the pilot project faced issues of pain, indeed it was pain that was their main driver in seeking support. Whilst the very high levels of pain reported by the participants was surprising, the link between pain, CP and quality of life is now well documented.⁹ As one Bobath therapist said:

I think, for me, for my guys, the biggest thing has been pain... and the bigger impact that pain has on adults than it does on children. I mean, you occasionally get pain problems but has never been as significant as it has been with the adult population. And how that impacts them is just so much more in terms of all their functional abilities and inabilities because of pain and how that limits their social life and all aspects of people's lives. Some to a lesser degree than others it is not such a big deal for everybody but I think for, I would say, probably, a hundred percent of the adults I have seen have all complained of pain as one of the major problems. So, that for me has been the biggest thing.

The therapists ascribed pain, contractures, spasms and other bodily problems to long term muscle and joint abuse coupled with long term posture, movement patterns and / or seating issues:

And, for me, one of the biggest things has been posture and wheelchairs. Stiffness and asymmetry and, actually, how to address those because they're one of the fundamental starting positions from where you can then take your treatment programme through... (therapist)

These problems have become amplified by the poor provision of suitable aids and adaptations, a lack of knowledge about how best to work with adults with CP and a lack of access to appropriate services. Wheelchairs, orthotic splints and other assistive equipment that might have been suitable when an individual was younger can quickly become problematic and disabling in adulthood:

I was also having problems with splints and things... I have a number of occasion where I have had a really old pair of splints that I was using and that I could walk in but they weren't supporting my feet in the same way... And when I went back to the orthopaedist she said "you need this kind of long leg splint..." But that meant that I couldn't walk as well... And it was really putting me off walking at all... So, I went back to Bobath to try and get help with that as well...

⁹ Dickenson, H Parkinson, K Ravens-Ceiber U et al (2007) Self-reported quality of life of 8-12 year old children with cerebral palsy: A cross sectional European study *Lancet* 369: 2171-78

New problems often crept up gradually over the years or existing ones became more pronounced due to a lack of appropriate rehabilitation and maintenance provision.

Growing up and growing older with CP, or at least the physical changes associated with this, was not something that many participants had contemplated or been informed about, although this varied with age. Some said that they had been told about the possible consequences of ageing when they were receiving therapy at Bobath Scotland and this had worried them greatly:

They mentioned it once and they scared the life out of me and I was... I just thought, you know, "no way" but I couldn't really envision it because I'm so mobile and stuff, and I don't see why I should age prematurely unless you can see it in my face or something but... eh...

Others had not been made aware of any potential problems. It was only after attending the adult therapy service that they had been given any advice on what to do should changes occur or how to moderate such changes. Thought should be given to how Bobath Scotland informs individuals about the potential effects of ageing with CP as although this is very necessary, it is counterproductive to unduly scare and concern.

Most of the Bobath therapists we spoke to said that they were aware of some of the issues associated with ageing with CP. Whilst the Bobath therapists were well versed on this issue, some discrepancies were found with health professionals and local authority representatives who did not see ageing with CP as a particular problem. Local Authorities and Health Boards were generally fairly confident in the adequacy of their services to meet the changing needs of people ageing with CP. They expected the needs of adults with CP would be met through the current care and rehabilitation policy context including initiatives variously described as 'ageing in place', 'self-directed support' 'personalised care packages', 'anticipatory services', 'enablement services' and 're-enablement services'. They did not see the need to develop specific targeted policies and procedures aimed at people with CP.

The Bobath therapists, many of whom had not worked with adults for a considerable period, had become aware of the problem through training and continued professional development, discussions with colleagues and also through simply looking ahead and deducing what were likely to become issues/factors in the future for the children and young people they have worked with for a number of years. During the course of their Bobath practice they have also learned more about specific issues such as pain and 'body structure and function' from training sessions with their London-based tutors. A therapist pointed out that while issues around ageing with CP are often thought of in physical terms with a focus on issues such as pain, reduced range of movement, fatigue, risk of osteoporosis and so on, one of the key things they have learnt from the pilot project has been the socio-emotional aspects of ageing with a lifelong condition like CP. These other factors were felt to

be at least as important to the ageing process as the actual bodily changes. These included the ageing of the person's support network particularly the parent:

not only is the person with CP ageing - carers are too! I know that sounds like stating the obvious but where the main carer is a parent, the time can come where it is becoming increasingly challenging for the person to give the same level of physical assistance during tasks that may have been relatively straight forwards before (therapist)

Also central to the ageing process was the absence of any mainstream knowledge base or specialist services to meet the needs of adults with CP which impacts on the everyday activity and routine of the person and their family.

This absence of services for adults with CP was widely reported by participants and their families and is discussed below.

The Adult Therapy Service

We specifically asked the adults to tell us about their thoughts on the adult therapy service, both in terms of how it was delivered and what benefits they felt they got from it. Given the very small numbers in the study and the lack of objective measures identified by the therapists that can be used in research, it was very hard to provide an objective evaluation of the actual impact of Bobath therapy on adults with CP. We can however report on their perspectives and feelings about the service and their own views on how it has helped them both socially and emotionally. All of the participants were really positive about Bobath Scotland's service and thought the adult therapy provision was to date the only service they had accessed that met their needs and requirements. One participant said:

Ah well absolutely, I mean, there's no, sort of, miracle and stuff but it's like I've said, it's just... it does help me a lot and I've always said that I feel more loose, you know, more flexible afterwards...

For this participant Bobath met most of his needs. He was looking for exercises for bodily maintenance, keeping strength in his legs, keeping them straight and helping ensure he remained mobile.

This positive feeling gained from therapy in terms of bodily maintenance was echoed by another participant who said that she felt "better and looser.." after a therapy session. Another said she definitely felt that the therapy had helped prevent her from experiencing an anticipated decline, it stopped her she said from "getting worse". She also feels the therapy helped her to be more able to do things such as standing and that it had improved her stamina and her overall sense of wellbeing. By going to Bobath she now felt that it was a lot easier to manage when she was out and about and that the therapy had helped her maintain her level of community involvement and participation.

Participants were unanimous in their praise for Bobath Scotland's therapists. Many have formed strong and trusting relationships and as some of our participants had attended Bobath as children these relationships were long standing and enduring. They thought that the therapists started from their perspective and listened to their needs and wants and took time with them. One participant says:

They are really understanding and I can talk to them well. I always found that they take the time to find out what is the problem which is really good.

She also said that her therapist always asked her what she wanted to do in a session and allowed her to lead the therapy. This involvement in decision making was seen as pivotal to the success of the programme.

Another told us:

...I felt that when I went along to Bobath that the best thing that they actually said to me was "What is it that you want?" and that was what --- said to me: "What is it that you want out of this?" and I have been able to work with them and doing what I want to do rather than just having things imposed on you....So, that's where I have just found everything so personalised and I have seen an improvement in my walking and probably my confidence as well – I was getting a bit nervous about going out on my own and walking and things. So, it has improved that.

For many participants the programme was not only good in terms of their physical wellbeing, it was also psycho-emotionally beneficial. They felt that they could talk to their therapists about many things other than just their physical health and that they were able to use the sessions as a chance to express their fears and their concerns about their condition and the impact it was having on their lives. They also felt able to talk about any particular issue that may have been bothering them that particular day and that the therapists would give the time to listen. Perhaps most importantly in this regard was that they felt that the therapists were experts in their condition and that they knew how to help them. This feeling was as a direct result of the strong bond that the participants had formed both with the organisation and with the staff. It is important here to mention that this bond was not just with the therapists but extended to all the staff in Bobath Scotland.

Bobath Scotland was also an important psycho-emotional source of support to participants' families and support networks:

Yes, because it is even more than just physio – Bobath is a support service and it is very much... that's what [..]was saying is that she trusts implicitly the therapists plus the fact that they are a support to the family as well... ... and they are not only giving their knowledge to the families and the carers, but they are a support to the family as well... So, they are even more than just a physio service there... they are more than that... (parent)

The therapists have become in many instances an important part of the participants' social circle, attending family celebrations and events.

They were also an important source of practical support. The therapists visited the participants' home if the need arose, many had in the past guided families through hospital treatment and aftercare and importantly helped people navigate and negotiate mainstream health and social care provision. This latter role was for many essential. Most of the adults did not have any other health professional working with them and this contrasts greatly with the experience of disabled children who are usually able to call on a team of therapists including OTs, physiotherapists, speech therapists and paediatricians who Bobath therapists could link with. Adults were not necessarily known to other services so making a referral for an aid or adaptation was much more of a protracted process than they were used to when working with children as there was no other prior involvement. It also placed much greater responsibility on the therapists.

The therapists told us that if they picked up a problem sometimes individuals get placed on a waiting list but it could be four or five months before they get seen. However Bobath Scotland practitioners were sometimes able to get a more direct referral and get a quicker appointment. They had the right contacts and knew who to talk to. They could advocate and actually prioritise and get these referrals moving. Previously participants had to rely on their GP who often did not know who to contact or how to help people.

The therapists said that they were still learning about which person or place they should be sending a particular individual to:

... well, it is still a bit of a mystery as to who it actually is that takes on... from a neurology point of view... that takes on the adults... I still haven't worked it out... it is different everywhere you are... every geographical area seems to be different... (therapist)

Navigating the health and social care system could be difficult because community services have been reconfigured so many times in the last few years that professionals working within departments were not sure themselves where responsibilities lay:

...I think that what is happening is that there is pots of funding for specific things like equipment or home assessment or whatever it was and depending on which geographical area you went to they had chosen to spend that money different... so the structure was different... so there might be an enablement team in this region but next door had chosen to spend it in a different way so they didn't have an 'Enablement Team' but they might have it under the name of something else... So, when a service like ours is working across all these different regions it is sometimes tricky to know... (therapist)

The therapists said that they found it difficult even though they knew what questions to ask and had contacts. It was so much more difficult for an individual to know where to start with their enquiries. As health professionals they had more ability to demand answers and could have more impact than individuals who either had to do it themselves or rely on family members. The therapists said that they could do “a bit of the detective work”.

This role was seen as invaluable by participants and their families. This of course might be a double-edged sword as while the therapists were willing to provide this additional support, the limitation of funding, time and resources could make this untenable in the long run. It does however suggest that there is a need for an advocacy role for this client group.

A recurrent theme to emerge in the interviews was that by attending Bobath adult therapy service people were given renewed “hope” and positivity. Participants were encouraged when they heard therapists suggesting that their functional decline and pain were not an inevitable outcome of having CP and that there was something that could be done to help them. Participants felt encouraged by therapists saying “we could try this, we could try that” even if it was not entirely successful. The intention was not about offering false hope and both sides seemed to recognise this:

What I have found since joining Bobath is that I have probably got a renewed... I don't know sense of things can get better rather than getting worse... I think until I was involved with Bobath I felt things... that I was getting a bit slower and struggling a bit more with things, and didn't know how to go about improving it. And probably the main thing that I want to tell you is that they have brought out hope for me and that is the main thing for me in terms of where I'm at with Bobath.

Participants unanimously thought that therapists understood their needs as adults and recognised that their concerns and needs were different from those of the children they worked with:

I think that obviously it is going to be quite a big change for them to go from young children to an older person but I think that with the training and things that they get from the centre down in London... I think that they are trying to tailor the therapy to a more adult approach but I have always found them really helpful...

All the participants felt they were treated like adults and not patronised. This is an important issue for organisations who have an established history of dealing solely with children and shows that the therapists and other staff have been able to adopt an “adult centred approach”.

Adults who received Bobath therapy as a child thought that their therapy regime was now significantly different as was their relationship to the therapist. One participant said it was different in two ways:

... when you're a kid and stuff like that, I think you're, sort of, being pushed too hard but then, as an adult, I can see the benefits of it. But now it seems more reasonable... but when you're a child and stuff like that, you don't really understand and you think that they are pushing you too hard...

Therapists they felt tried to make it fun for children and tried to coax them into doing exercises, whereas adults knew what they was required of them and why. The therapists echoed this and said adults tended to be very motivated and actually wanted to be in the sessions. Children were there because their parents or guardians brought them along and they were being told that this was what they had to do. The intrinsic motivation from the adults was the big difference between them and some of the children that attended. While they did not want to generalise, the therapists felt that when they had an adult on board who was motivated then sometimes achieving change was a little bit easier than it was with some children, even although adults had long established patterns of movement and posture which had led to protracted and chronic problems.

In terms of the facilities and organisation at Bobath Scotland HQ, participants were very positive in their views about how welcoming all the staff were and also about the therapy rooms and the kitchen set up. They thought that they were accommodated very well when session schedules were arranged. Some participants were content with the spacing of their sessions, however, others would have preferred shorter intervals between sessions, and all participants would have preferred to have received more sessions. There was a lot of agreement about the need for Bobath Scotland to carry out outreach work across the country, not only in terms of providing therapy but also in terms of providing training to other practitioners to carry out therapy. While Bobath Scotland HQ was praised and participants and their families elicited enjoyment from their visits there, it was generally recognised that its location would be an issue for those who did not have their own transport. Both participants and therapists recognised that financial constraints obviously mediated the availability and running of the pilot project and would continue to mediate any future development of the adult therapy service. Likewise, personal and family resources would also mediate an adult's access to any service that Bobath Scotland could offer them.

Access to services

We also asked our participants about their experiences of other health and social care settings and the sort of support they had received in mainstream healthcare. Their views and experiences presented a stark contrast to those of Local Authorities

and Health Boards we spoke to who were confident in the adequacy of their policies and practices to meet the needs of adults with CP. A common refrain from participants and their families was that individuals with CP “dropped off” the radar of mainstream services when they reached adulthood:

Adult Services in Scotland... you have no condition when you are nineteen... it goes away...

Another participant said of mainstream services:

Yeah because that's the thing, they cater to kids no problem and that's great because they're very vulnerable and I think, you know, life doesn't stop when you become an adult...It's important that, you know, that things keep going because they can do the best job for you when you are a child but, you know... em... before the adults scheme, you've been thrown out cold with nothing.

This may be a crucial mediating factor in why participants and their families felt that the adult therapy pilot project was such a positive and vital development. There was a bit of debate among therapists as to whether this was a valid point:

Probably ... they ring around... and they try to find a service and discover us... but I don't think that people start off knowing that there is a place like Bobath. In their discoveries they discover Bobath and they say “We've never heard of you”

Almost all of those we spoke to reported bad experiences when attempting to get therapy and other support from mainstream Adult Services. This was true even from those services with a specified disability remit:

I don't think that there are good services out there apart from Bobath and that's obviously in [my] area and I can't speak wider. I have gone along to the [local rehab unit]. I haven't been that impressed...

Services it would appear were either non-existent for adults with CP or wholly unsuitable and inadequate. Some participants who had attended Bobath Scotland as children had sought to return there to get therapy as adults before the pilot project began. They had previously attempted to get help from mainstream physiotherapy and Community Disability teams and had been very disappointed in the service and reception they received. One participant speaks about receiving some therapy locally:

I was just getting on a bike. It was a joke.

She felt that it was very difficult to get therapy when she became an adult as “there was nothing”, “Just that bike”. The local provider she went to did not know about CP and the service was geared more towards people who had a stroke or other

condition. There was little understanding of CP or how it might affect her as she aged and her needs changed. She also felt that the service did not listen to her or ask her about her concerns.

Another participant was told by her GP that there was a 19 week waiting time for physiotherapy and she would not get physiotherapy unless she had a 'problem'. Another participant explained how she had returned to Bobath Scotland as an adult to get some help after a very disheartening response from her local rehabilitation team regarding severe back pain that she was worried about. In this case the professional did not listen to her or even accept that there was anything they could do to help her:

... I went to the local Rehab centre..and the physio basically sort of said to me "Your back pain is a chronic problem and you just have to learn to manage the pain..." and I found that really quite off-putting and I thought "Well, I don't want to just manage the pain. I want to get to the bottom of it." So, that's when I contacted Bobath.....

She summed up the significance of Bobath Scotland by explaining that she found it really helpful and supportive in comparison to going to the Health Service where she had been told that she had just to get on with it. She said that in her experience a Bobath therapist would never ever say go away and "Just manage the pain..."

Participants were unanimous in their support for the delivery of a service such as the one offered by Bobath Scotland and were adamant about the need for some sort of adult therapy service to continue once this pilot study was completed. While some were aware that the pilot project had a finite life, others were not aware of this and were perplexed and concerned when the matter was raised. One participant said:

I was disappointed when I found out that they were discontinuing it until they found more funding. I was, kind of, disappointed in that because there's stuff... there's a lot of adults that need it in different ways... so I think it is, you know...

The success of Bobath Scotland as a fundraiser was often sighted by individuals as reason enough not to have to consider the end of the service:

I hadn't really thought about it... I mean, I don't know... I hadn't talked to Bobath about it but I would have thought that they would have been able to get the funding because, you know, they have kept it going through a recession. So, I would imagine that if you can keep it going throughout a recession a finding funding – I don't think that they will have a problem in finding it... Now, whether they need more and finding more people to come in and that is where the problem is – I don't know but I would be surprised if they couldn't keep it going... But then I don't know. I haven't asked the question.

The organisation might perhaps want to consider how in future it prepares its exit strategy as this withdrawal of services did cause some worry to the participants. People for example wanted to know what would happen to them and everyone else if the adult therapy service was no longer running:

I would be worried about where to get therapy from.

Participants wanted the adult therapy service to receive secure funding. They wanted somewhere they could go to receive ongoing support and also somewhere they could go should their impairment worsen and their health needs change. They felt that Bobath had the sort of knowledge that they needed and that without this there was nowhere else for them to turn:

...there wouldn't really be anyone there... and so I wouldn't get any physio...

While some parents were resigned to the lack of support offered to adults with CP by health and Community Disability Teams and said that it was understandable with restricted resources that funding is always target at conditions that are more prevalent in the population, other parents were adamant that a failure to fund support for adults with CP was counterproductive and actually wasted resources further down the line:

I think, personally, that they have got to look at the service that they are providing and surely if you recognise that there are some conditions, long term conditions that should be managed throughout their lives it would prevent contractures and expensive bits of surgery that might have to happen in later life because nobody is addressing the problem throughout their life. So, yes it is maintenance for somebody's life but by doing that maintenance you are preventing expensive procedures later on.

Outcomes

This evaluation was able to report the impact of Bobath therapy on adults with CP in terms of their own perspectives and feelings together with those of the therapists. Both the therapists and the adults reported seeing improvements in individual function and performance during and after the adult therapy programme. The therapists recorded these changes, however these outcome measures were not presented for inclusion in the evaluation process. The therapists have had problems identifying robust outcome measures that would enable them to fully capture all the changes that were made by individuals and therefore provide them with a more rigorous way of reporting what was achieved through the therapy programme. Their challenge was identifying outcome measures that detected changes that were “meaningful” not only to the individual, their support network and their therapist, but also to funders, researchers and policy planners. Some of Bobath Scotland's therapists used the Canadian Occupational Performance Measure

(COPM) which identifies a person's main concerns and measures how they rate their performance and satisfaction regarding specific tasks at the outset of therapy and again at its conclusion. A person has to rate what they think their current performance is for each task and then what their satisfaction is with that performance. Both are rated using a 10-point scale where the higher the number, the better a person perceives their performance and satisfaction to be. Some therapists also used video evidence with some adults and this allowed them to monitor an individual's function and movement patterns before, during and after the therapy programme. Outcome measurements such as these were not supplied as part of the evaluation process and even if they were it would be problematic to assess their validity. A COPM score was supplied for one individual which purported to show significant change over 3 months which in terms of therapy for adults was said to be a very short period of time. These results were said to be "very real and very relevant" for this individual and made a tremendous difference. However the format of the data supplied and the fact that it was only for one participant make any objective analysis impossible carry out.

The therapists stressed that they have sought a more robust and "meaningful" method of measuring outcomes, but that this was difficult to do for a number of reasons. For example, their therapy approach is designed to be iterative and to evolve over the programme of sessions to allow them to take account of the changing need of individuals and their understanding of their condition and the problems they want to address. What might be a focus of concern and point for work that has been recorded and measured at the start of the therapy programme might not be the same one that is recorded and measured at the end of the programme. Often at the beginning of the sessions it was quite difficult to identify issues that some adults wanted to work on and they were just really keen to get any kind of input, whereas others came with specific issues that they knew that they wanted to work on. In the former group it was harder to measure how they were at the beginning and how they were at the end of the therapy. In addition many of the changes were not easy to measure from a traditional physiotherapy, numerical viewpoint such as improved body awareness and confidence – issues which were significant to most of the adults. These measures were also not always sensitive enough to pick up every change and so small changes achieved that were really significant to an adult were not registered via standardised measurements. This also occurred when they worked with children, however it was a more significant problem with adults as the focus was often on maintenance and stopping deterioration rather than developmental changes. The therapists had to use these measures because that is what is required in the health sector. They understood that "soft" outcomes were also very important to measure. However, it is difficult to measure the impact of therapy on confidence, social life, family life, etc. Therapists believed that Quality of Life Measures (QoL) are more important, especially for adults, although this would depend on each individual and their specific circumstances. Ideally they would like to use QoL measures and one of our key recommendations would be that Bobath

identify an instrument that would be suitable for use with adults with CP. The therapists and management acknowledged that this was something that they would want to seek help with if the project was to continue in the future. However they felt they were in a quandary as statutory funding bodies wanted “hard”, quantitative data indicating whether providing Bobath therapy to adults with CP would save the NHS any money, something which was very difficult to say, and voluntary funding bodies wanted “soft”, sometimes almost ‘tear-jerking’ - qualitative evidence.

The therapists also recognised that there was a need for research that examined what works best in terms of therapy for adults with CP and also that compared how the Bobath therapy approach differed from mainstream therapy and examine what this meant in terms of outcomes for this group. They explained how Bobath therapy differed from other therapy provided by mainstream services. For example the therapists had a lot of experience of working with individuals with CP of all ages, have had training in relation to working with adults, had a greater depth of understanding of CP and sensitivity to the diverse nature of the condition, and could anticipate what problems might emerge in future and how to manage such problems. They worked as a trans-disciplinary team which they felt was a very important aspect of their approach. They worked very closely with children’s parents and carers and this therapy ethos had been extended into the adult pilot project and working together with adults’ support networks. They offered a “bespoke” approach to the issues faced by people with CP whereas mainstream therapists may just offer generic approach to treatment in their clinic followed by a prescription of self-management exercises to be carried out at home. The therapists aimed to make lasting changes at a sensory as well as a motor level and positively influence an individual's function as well as prevent or limit contractures and other problems. It is not possible at this juncture to give an objective analysis of each approach or to evaluate outcomes either through this study or a review of the literature. This is our other key recommendation.

Conclusion

In concluding this report, the overriding message from this evaluation was that there was a need for Bobath Scotland's adult therapy project and that for those who used it the pilot project had met their expressed needs and requirements.

We think that there are two key issues that need to be stressed; first, as people with CP age the extent to which they are affected by CP, changes and second, health and therapeutic services do not recognise or take account of these changes. CP is seen as a static, non-progressive condition, and so are people's needs. Many adults with CP face increasing problems as they age and this need is not acknowledged or recognised and as a consequence service providers do not know what works best or how to help them.. Adults with CP, our research would suggest, are facing greater difficulties in their lives than service providers know or understand and these are multiplied because they are not able to access appropriate rehabilitative support. Mainstream services are failing to meet adults with CP's needs.

All of the emphasis on growing older with CP is focussed on the transition for young people as they leave school and move into adulthood. Here it is focused on 'life skills' training with little attention or no attention being paid to changes in the effect of CP on what people can and cannot do or on future therapeutic needs and body maintenance as they age. CP should be viewed as a lifelong condition and should be treated in the same manner as other long term conditions. Adult Services should draw up plans to develop a specialist service for adults and older people with CP to ensure that the health needs of people with CP are met at all ages and not just during childhood.

The participants and therapists' views clearly suggested that Bobath Scotland's adult therapy service was needed, was beneficial and should be developed further. We would endorse this view and would recommend three main courses of action. First Bobath Scotland should seek to collaborate with other organisations who work with adults with CP to set up an extensive epidemiological study to look at how people experience ageing with CP and how this impacts on their service needs, Second Bobath Scotland need to examine what works best for this group and to establish clinical guidelines for good practice. Third, and lined to this, Bobath Scotland should look at identifying more robust outcome measures which are better suited to working with adults with CP.

