



SUPPORTING WELLBEING

Psychological Considerations for Supporting
Individuals with Cerebral Palsy

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“ Wellbeing can be understood as how people feel and how they function, both on a personal level and a social level, and how they evaluate their lives as a whole”

The Mental Health Foundation

It takes into consideration matters relating to individual's health, happiness and success. It includes having good mental health, high life satisfaction and a sense of meaning or purpose.

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Service Specification Proposal

1. Objective

This proposal aims to provide recommendations on contributions that Clinical Psychology might add to existing support services being offered at Bobath Scotland. This is in recognition that mental health is a necessary consideration of overall health and well-being.

The content of this proposal is based on a combination of the currently available evidence base, a review of existing support services being offered at Bobath Scotland and consultation with those who have lived experience of CP; either as an individual diagnosed with CP and or their families/carers. In addition, practitioners specialising in CP support services at Bobath and in related fields out with were also consulted.

2. Introduction

Population prevalence of mental health difficulties:

Publication of the 2014, Adult Psychiatric Morbidity Survey¹ highlights that, every week, 1 in 6 adults experiences a common mental health problem, such as anxiety or depression and 1 in 5 adults have experienced suicidal ideation. Similarly, reported rates of mental health difficulties in children indicate increasing prevalence, with an estimated 10% of children over the age of 5 having a significant mental health disorder².

Linking physical health/disability with mental health and wellbeing:

Mental and physical health are interconnected and chronic health conditions are widely known to increase the risk of developing mental health difficulties, such as anxiety or depression³. People with disabilities or chronic health conditions are reported to be 3-4 times more at risk of developing anxiety and depression^{4,5}. Indeed, children with disabilities, particularly those with 'chronic cerebral disorders', are reported to be at higher risk of experiencing mental health problems compared to their non-disabled peers^{6,7}. However, research suggests that the elevated risk of mental health need is not *necessarily* related to the person's specific disability, rather it may be linked to associated challenges such as stress, pain management, fatigue, general coping skills, family and social supports, social exclusion, bullying, reduced employment, social and educational opportunities⁸⁻¹¹.

Cerebral Palsy specific:

One of the most common causes of life-long disability is Cerebral Palsy (CP)¹² which was traditionally viewed as a "static", childhood condition¹³. Health service supports have typically been accessed via the paediatric health sector and therefore focussed around the needs of the individual within the context of their childhood physical development.

However, there is an emerging shift in our understanding of the life-long condition of CP. More recently published mortality data significantly differs from the rates that were reported from circa 50 years ago. Current life expectancy for adults with CP, who have mild to moderate disability, is now only *slightly* reduced, compared with the non-disabled population¹⁴. The near normal life expectancy of adults with CP has shifted the focus from seeing CP as a static condition, acquired in childhood, to recognising that there are noteworthy changes in the presenting needs associated with the ageing process of living with CP.

Non-static features of CP across the lifespan (ageing with CP):

Recent literature highlights that age-related physiological changes occur earlier in adults with CP, and the prevalence of secondary conditions, such as pain, osteoporosis, fatigue, musculoskeletal and joint problems is higher in adults with CP, compared to age-matched adults without CP⁸. These reported changes, associated with ageing with CP, have led to an increasing awareness that the original presenting symptoms may indeed change as the person matures. Therefore, individuals with CP may present with changing support needs across their lifespan and connections with support services is necessary to monitor and offer support in response to these potentially changeable needs.

Variability in access to services or in help seeking of individuals with CP:

Access to support services varies considerably across the country. Supports are considered to be somewhat more readily available, although not necessarily CP specialist, in mainstream healthcare for children and young people within Paediatric services. Supports are also often physically focussed and the wider needs of individuals, including the mental health and well-being of individuals with CP and their families, it is thought, to fall through gaps in service provision. In addition, mental health needs may be overlooked by individuals with CP themselves, and their families as they endeavour to 'get on with things'. Overall, the lack of identifying and prioritising an understanding of the wholistic impact of living with CP leads to greater risk that mental health needs are not being timeously recognised, supported nor advocated for in the development of supportive services for individuals with CP.

A recent review¹⁵ examined the physical and mental health issues and health service use patterns among adults with CP. Findings from this review highlight significant physical and mental health issues were being experienced by this population. The paper also noted considerable gaps in the literature; suggesting variable prioritisation of researching for better understanding within this population specifically. It was also highlighted that disparities, related to health and health service issues, were evident between children and adults with CP. In addition, there were disparities in the findings across individuals with CP compared to other clinical populations and with the general population. This would support the anecdotal reports of a lack of consistency in nationally delivered service provision/availability and uptake. It is now more widely understood that many young adults transitioning from child services to adult services are believed to fall through service gaps; resulting in their changing physical and mental health needs going unmet. This increases the risk of the potentially bidirectional impact of physical and mental health on their overall quality of life.

Compounding challenge of unmet mental health needs on physical disability:

Left untreated, mental health difficulties can contribute to poor physical health³. Therefore, understanding the potentially symbiotic relationship between physical and mental health needs is imperative to guide support service development, in order to meet service users' needs accordingly. Green (2018)³ stresses the importance of learning to recognise when someone is at risk or is displaying symptoms of behavioural and emotional difficulties. Green stresses that this is a key element in improving mental health and argues that early intervention is critical to prevent short-term difficulties from becoming prolonged and debilitating mental health conditions. However, while supports tend to be accessed in accordance with presenting physical and early communication needs, current care pathways do not appear to proactively and systematically identify the potential mental health and well-being impact of CP.

Mental health is linked to how a person feels, thinks and behaves. Difficulties associated with mental health can result in daily challenges seeming overwhelming, which in turn can lead to increased anxiety, social withdrawal and have a negative impact on your mood and overall QoL. Consequently, this serves only to further compound difficulties and thus the cycle continues when needs are not identified and supported.

Based on the available literature and consultation with those who have a lived experience of CP, understanding mental health needs is considered to be an additional essential aspect of the person-centred support provided. This should take into account the varying needs experienced at different points across the lifespan. The needs of key individuals within their daily support network, should also be considered. Based on the findings from this service scoping exercise, it would be recommended that assessing an individual's mental health should be a key component of routine health screening along with consideration of needs for support across their wider support/family system.

3. Methodology of Service Scoping Exercise

Clinical Psychological consultancy was sought to consider the rationale, aims and scope of this exercise. It was agreed that the consulting Clinical Psychologist would undertake the following:

- Attendance at the annual conference, to establish a context for this work.
- Familiarisation of the services currently being provided at Bobath Scotland.
 - Shadowing various parts of the service, e.g. Bobath Babies, Initial Assessments, individual therapy sessions.
 - Consultation with staff regarding the specialism of their roles working with individuals with CP and their wider systems.
 - Identifying staff perceptions about areas of scope for service development at Bobath Scotland.
 - Consultation with service users, with lived experience of CP (individuals diagnosed with CP as well as parents/carers) and establishing a service-users based understanding of service development goals.

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- Ascertaining national service provision through consultation with national mental health specialists in Paediatric and Older Adult Clinical Psychology.
 - Review of the key relevant literature and policies.
 - Provide a written summary of the service scoping exercise, including service development proposals.
 - Present findings and proposals at the Board of Directors Meeting on 19th February 2019.

This exercise was undertaken by Dr J Nisbet, Chartered Clinical Psychologist across 2 days per month between October 2018 – March 2019. In accordance with professional practice guidelines, this piece of work was discussed within professional clinical psychological supervision.

4. Summary of main conclusions:

Services Currently Being Provided at Bobath Scotland:

Bobath Scotland is a nationally available service providing support services to individuals diagnosed with CP, their families/carers and wider professional support networks. The Bobath Scotland team currently consists of specialised physiotherapists, occupational therapists and a speech and language therapist who work together to provide therapy for children and adults with CP through the Bobath Therapy Concept.

The ultimate goal of the Bobath Therapy approach is to maximise an individual's functional ability, where functional impairment arises from neurological conditions, such as Cerebral Palsy, regardless of the severity, age or accompanying disabilities.

It comprises combining occupational therapy, physiotherapy and speech and language therapy with aims of increasing overall movement, communication and functional ability. The multidisciplinary combination was designed specifically to consider the main aspects of a child's development and help them gain the skills required to explore the world, communicate their needs and actively participate in all aspects of their lives.

Bobath Scotland delivers the following services:

Bobath Babies

Providing support to children 0-2 years and their families post diagnosis.

Individual Therapy for Children

Providing a block of intensive therapy for children aged 2-6 years, funded through Big Lottery Funded - Right Start Programme

Providing blocks of intensive therapy for children of any age through Scottish Government CYPFEIF & ALEC Fund and also through self-funded families.

Providing regular therapy for children who have attended intensive blocks but have little community support through self-funding.

Bobath Buddies

Providing social and skills development support to children 5-11 years through a holiday club aimed at developing physical and communication skills.

Teen Academy

Providing social developmental support to young people aged 14-18 years through a holiday club aimed at developing a range of life skills, widen peer contacts and gain some age appropriate level of independence.

Adult Services

Providing one of consultancy appointments and initial therapy assessments either at the centre or through home visits supported by the R S Macdonald Trust.

Helping Hands

Providing therapy and support to adults through a heavily discounted scheme supported by the R S Macdonald and Robertson Trusts.

Outreach

Providing support to children, YP and their families across Scotland.

Consulting and providing training to the wider systems supporting these families, such as health professionals, social care partners and educational professionals.

Bobath Scotland also provides supports in the development of additional self-led support groups, fund raising, promoting information sharing and signposting individuals to services, information and additional supports of relevance to CP.

Bobath Executives sit on relevant national strategic forums and actively network to ensure that representation from Bobath Scotland feeds into the important national strategic developments. This provides a highly specialised, experiential perspective to developing national strategies, such as the recently published National Action Plan on Neurological Conditions (2019-2024).

Bobath Approach:

Practitioners were observed to provide highly individualised, assessment-driven and goal directed supports to service-users. There is clearly a person-centred and whole-person ethos to the supports provided by Bobath Scotland staff. In addition, the interests in the overall well-being of service users was an apparent priority in the motivations of therapists providing support. This is also reflected in the service development directions thus far. Staff clearly delivered on the Bobath Therapy Concept's problem solving and goal directed approach.

Staff demonstrate extensive and highly specialised knowledge, skills and experience in the field of CP. Service users noted this was of particular value to them and differed from their experience of mainstream supports, previously accessed.

Multidisciplinary staff work seamlessly together, delivering support and guidance to service users. Whilst drawing from their respective professional therapeutic knowledge and skills, Bobath Scotland staff practiced with utmost professionalism, warmth and commitment to collaborative practice, both as a staff group and in partnership with service users in addressing the goals agreed at intake. Developing a psychologically informed approach to their practice fitted extremely well with the staff group's interests, therapeutic styles and service developmental direction thus far.

Service User Perspectives:

Service users consulted were extremely positive about the joined up multidisciplinary supports they have received from Bobath Scotland. Many described having previously received piecemeal input from mainstream services. A lack of joined up team approaches was reflected. They described having to attend numerous individual appointments across different healthcare bases or departments for physio, SALT and OT. It was noted that the lack of joined up working was more challenging. Some reported experiencing a lack of resource availability, with no particular service seeming to fit their specific needs, precluding them from obtaining supports. Others reported being seen across a range of health services, none of which were CP specialties and some which felt like a poor fit for their particular presenting circumstances. This account was commensurate with the literature highlighting e.g. younger adults being seen in older adult services, musculoskeletal/stroke or disability services. Others reflected significant difficulties in accessing supports; often being redirected from the various services sought. One example included a family seeking help following concerns regarding their child's behaviour. They required help to understand if the behaviour was developmentally appropriate, associated with challenges arising from CP or reflective of other neurodevelopmental concerns, such as a social communication disorder, such as Autism. This particular example highlighted the struggle individuals and families can experience managing the day to day challenges associated with CP whilst also expending significant energies into trying to gain access to appropriate supports. It is not unsurprising that when these endeavours remain fruitless, individuals may either give up, try to just get on with it themselves or become despondent.

Some noted that they would have liked to have been linked with the organisation at an earlier point in their journey and that there was a need for wider general practices to be familiar with and signposting families to Bobath Scotland. This reinforced the view that the development of a clear pathway of care and support is needed. Variability of access to supports is anecdotally evident from the reports of Bobath Scotland service users. This also is commensurate with the recently emerging literature reporting on a need for greater consistency of support service availability for those living with CP.

In consultation with adults with CP, parents of children with CP and experienced staff, the enthusiasm for understanding the psychological impact of living with CP was consistently agreed as a current support gap and priority.

Consultation with National Representatives for Paediatric, CAMHS and Older Adult Clinical Psychology

National leads for Older Adult Psychology and Paediatric Psychology were consulted with regards to ascertaining what mental health supports are currently in place for individuals with CP. In addition, Senior Clinical Psychologists within Paediatric services across Scotland were consulted. Responses were obtained from the following health boards:

Greater Glasgow & Clyde, Dumfries & Galloway, Lanarkshire, Lothian, Highland, Ayrshire & Arran and Borders.

Overall, there was consensus that across services delivered over the life-span, there were no clearly defined specialist mental health services for individuals with a diagnosis of CP.

Within children's services, a referral would typically be accepted to Paediatric Psychological Services if the individual was struggling with their condition or an associated medical procedure that was required. If their difficulties were not condition specific, they would have to seek support in CAMHS, if they reach criteria. Tier 3 CAMHS would require individual's presenting symptoms to meet diagnostic criteria for a mental health condition, such as an anxiety disorder, depressive disorder etc. Should the difficulties be sub-threshold, this would preclude them from accessing supports in CAMHS. Query ASD/Autism presentations would be routed via CAMHS but this can be difficult to unpick whether the presentation is likely a result of aspects associated with their CP or comorbid ASD/Autism. This can create interruption and at times a block to obtaining support as confusion surrounds where such cases should be seen. This often leads to referrers or families being sent to other professionals to obtain information about the child's presentation, e.g. school teacher, Educational Psychologist in order to clarify where it might most appropriately sit.

Colleagues specialising in neuropsychology noted that there may be occasion where they would see individuals for specific neuropsychological assessment for cognitive function. The route for referring into paediatric psychology was varied; some GP, some Paediatrician, one from the neuro department. This reflected a lack of clear pathway which compounds the difficulties navigating where supports might be accessed.

However, as was the consensus, all clinicians noted that the numbers of individuals with CP they have seen in their respective services were, in their opinion, unfathomably low. One Consultant Clinical Neuropsychologist concluded that where people have evident physical disabilities, these are often the primary foci of support and intervention. This reflects Rosenbaum & Gorter's (2011)¹⁶ reflection that traditionally 'fixing' of the biomedical impairment, to enhance function, was the primary goal (although not reliably the outcome) of intervening in childhood disability cases. Rosenbaum highlights that the complexity of the biomedical underpinnings of conditions like CP, and the paucity of specific 'treatments' have provided few opportunities to effectively 'treat' biomedically, where the goal was to prevent or 'cure' conditions.

One clinician also reflected that it can be difficult to recognise mental health problems in some individuals with CP. They also noted surprise and concern regarding the lack of referrals received for cognitive assessment, that guides understanding about an individual's developmental and intellectual abilities and support needs. They went on to conclude that

this may well contribute to a great number of individuals' ability levels being grossly misunderstood. This could result in an individual not receiving appropriate access educationally and therefore receiving insufficient stimulation or being left to anxiously fail in an educational placement such as mainstream school. It was also noted that often much of the support is being provided within school settings and not necessarily with specialist psychological input.

In conclusion, this exercise has ignited enthusiasm from these specialists to speak together about this issue. There was clear consensus, across individuals with lived experience of CP and professionals, that the psychological needs associated with living with CP was not sufficiently prioritised but evidently needed. All agree that future service developments should incorporate a wider health and well being approach. This should therefore include mental well-being as a core element of this.

5. Proposed Framework For Service Development

Rosenbaum & Gorter (2011)¹⁶ present a model which is of particular value to consider as a framework for developing services for individuals living with CP. This model has been developed in accordance with the WHO International Classification of Functioning, Health and Disabilities 2001 (ICF)¹⁷ framework (Figure 1).

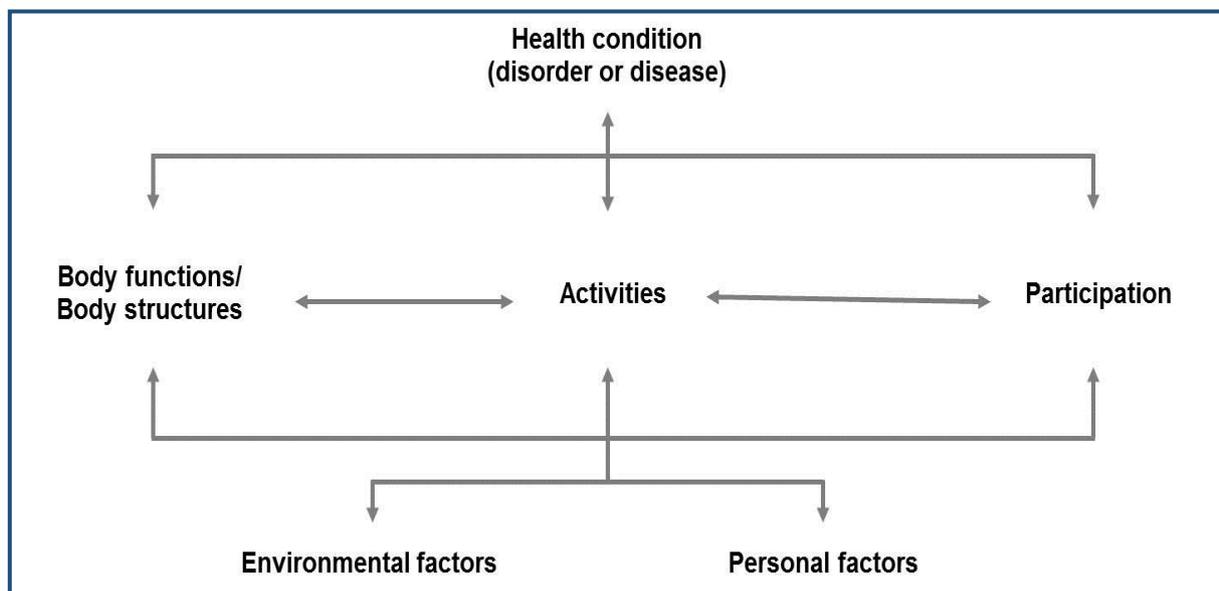


Figure 1: The International Classification of Functioning, Health and Disability (ICF) 2001

The ICF Framework presents a neutral, non-hierarchical framework for thinking about health as well as functional ability from a more inclusive perspective. The ICF also considers the importance of psychological function, conceptualised under body functions. They propose that the traditional focus on physical ability/disability is not necessarily the primary focus of support. Rather, the non-hierarchical and inter-relational framework supports the idea that

affecting change in one area may increase the likelihood of benefits across other areas of the framework, enhanced through a promoted overall sense of wellbeing.

Huber and colleagues (2011)¹⁸ presented a more dynamic and empowering definition of health which sits most appropriately with the inclusive vision of those associated with Bobath Scotland:

“Health is the ability to adapt and to self-manage” Huber *et al* (2011)

Following on from the ICF Framework, Rosenbaum and Gorter propose a number of areas for focus. It is their intention to encourage those working in the field of disability to apply these concepts in their work with individuals and their families. By embedding these identified areas within the relevant components of the ICF framework, Rosenbaum operationalises a health & well-being focus for support planning what might be most beneficial those living with, e.g. CP.

Referring to these areas as the ***‘F-words’ of childhood disability***, they provide key areas for promoting inclusion. The associated ICF components, under which they believe these may fall, is provided in the brackets.

ICF Components

- Function - *(Activity and Participation)*
- Family - *(Environmental/Contextual Factors)*
- Fitness - *(Body Structure & Function)*
- Fun - *(Participation & Personal Factors)*
- Friends - *(Personal Factors & Participation)*
- Future - *the authors promote a need for service providers to be thinking positively about the future from the outset of their involvement with families.*

With advances in thinking about health and well-being, this is a welcomed development from the traditional models of care, where ‘fixing’ the physical condition was typically the primary, and in many cases, the only focus for service provision.

Additional key factors for consideration include understanding an individual’s capacity and performance, in accordance with their physical disability. However, importantly they discourage applying previously held standards of considering an individual’s capacities in relation to typical ‘normal’ development. They highlighted how this also influenced interventions to attempt to remediate the individual’s function according to ‘typical normal’

ways of doing things in a bid to 'avoid forming bad habits' or promote 'normal' acquisition of skills and function. Gibson *et al.* (2011)¹⁹ stress that this approach may have hindered developmental progress and participation on '*the alter of normality*'. Instead, Rosenbaum and Gorter argue that *how* things are done is not the primary concern, rather the 'achievement' in their participation is of greater value than the 'normal' way of doing something as the only goal.

In addition, the proposed framework supports the importance of providing opportunity for experience. It is recognised that individuals with disabilities are often deprived of experience, for a variety of reasons. This framework provides a specific focus to consider opportunities for participation. This directs those supporting individuals with CP to consider and promote opportunities through their interventions. This might include addressing identified barriers, where possible. In discussion with various adults with lived experience of CP, the importance of promoting participation and encouraging those surrounding children during their early years to convey this priority for participation opportunities was extremely prominent.

In the field of chronic health conditions, there has been significant focus on the relationship between perceived Quality of Life and psychological wellbeing. QoL relates to the functional capabilities individuals should have to pursue their self-defined sense of well-being based on their personal values and priorities. It also includes consideration of an individual's sense of personal achievement, life satisfaction and well-being.

This framework is more inclusive of the various areas that may affect an individual's sense of well-being, with appropriate consideration of the importance of psychological health. The areas identified across these 'F-words' and ICF Framework are associated with many of the dimensions known to impact an individual's perceived QoL. The applicability of this framework for considering person-centered, values-based approaches has scope for developing personalised interventions in recognition of the heterogeneity of need in this population.

6. Findings

This service scoping exercise identified that there is a lack of CP specialised services available nationally. Support services available within the NHS appear to vary across Health Boards but supports which are available typically provide a predominantly physical focus as part of wider neurological or chronic health related services. There appears to be a lack of strategic service planning around the lifelong and whole-person impact of CP, specifically.

There is growing evidential and anecdotal recognition of the importance of providing supports beyond physical therapy to address the overall health and wellbeing of individuals living with CP. Bobath Scotland, as specialists in the provision of therapeutic supports to enhance function and communication, are strong ambassadors addressing wider needs that

contribute to enhanced perceived quality of life in individuals with CP. They have a specific interest in formalising the development of psychologically informed approaches to the work that they do. However, to date, the psychological sequelae associated with CP appears to have received little designated focus within wider national strategic planning.

The findings of this scoping exercise support a rationale for promoting the development of psychologically informed therapeutic supports for individuals with CP. Bobath Scotland is in a strong position to pioneer such an approach, given its existing person-centred model of practice and practitioner skill-mix. It would be advised that in this case, outcome evaluation should be incorporated into the work undertaken. This would provide valuable contributions to the evidence base for promoting addressing an individual's needs from a wider health and well-being perspective. Such information would provide useful support when promoting psychologically informed ways of working with wider national service providers. Such developments would, it is hoped, create the possibility to develop exciting opportunities for multidisciplinary and potentially multiagency working in the future. Partnership working is a priority for Bobath Scotland.

In the meantime, there is a need to raise awareness of the specific needs to inform wider care pathways and service developments across sectors. With the current model of service provision across the NHS, there is limited evidence to suggest development of clear and comprehensive care pathways for individuals with CP. Continued engagement in strategic discussions around the needs associated with neurological conditions is required.

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