

Title: *Community based family and carer-support programmes for children with disabilities*

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Conflict of interest statement: The authors declare no conflict of interest

Word Count: 3847 (inc box text) (Max 4000)

Abstract: 147

## **Abstract**

Children and young people (CYP) with disabilities face multiple challenges and unmet health needs. There is considerable variability in quality of health services across the UK for these children.

Families report that they experience lack of information or misinformation about health, social care and education of their child. They also highlight a desire to engage with other families of CYP with disabilities. There is growing evidence that community-based group interventions in under-resourced settings are effective at improving quality of life for both CYP with disabilities and caregivers. Few similar interventions or evidence exists in the UK.

This article provides an overview of relevant evidence and, using cerebral palsy as an exemplar, discusses the potential for group-based programmes for parent carers in the UK.

Groups would aim to address information needs, support providers to deliver evidence-based care, and thereby improve the health and wellbeing of CYP with disabilities.

Keywords: caregivers; cerebral palsy; children; community-based interventions; family; disability; family

## **Introduction**

In the UK, 8 per cent of children live with disabilities, with the majority of them cared for at home. Consequently, most home support and care for Children and Young People (CYP) with disabilities is provided by families or carers. Caring for a child with disability can be extremely rewarding, but also a great challenge for caregivers, as it places an added demand on both mental and physical resources, compared to caring for children without disabilities.

Consequently, parent carers may experience more mental health issues, with higher levels of stress and parental depression compared to carers of children without disabilities. They may be given insufficient or inadequate information or support, and there is a common perception of poor coordination between health, social care and education in providing support. These issues undermine care provided from families to CYP with disabilities.

This article provides an overview of the pertinent evidence and discusses the potential for UK-focused group programmes to (1) address gaps in families and carers information needs and (2) support providers to deliver evidence-based care that will improve the health and wellbeing of CYP with disabilities. We use Cerebral Palsy (CP) as an exemplar disability, as this is considered to be one of the commonest childhood physical disabilities, it encompasses a wide range of severity and is associated with a number of other impairments.

## **Epidemiology, presentation and impacts of CP**

CP is an umbrella term for a range of non-progressive syndromes of movement, muscle tone and/or posture, caused by damage to the developing brain up to age 2 years. Globally, 17 million people live with CP (2.1 cases per 1000 live births), with an estimated 110,000 cases in the UK.<sup>1</sup> The primary risk factor for CP is preterm birth; infants born before 28 weeks of gestation are approximately 50-times more likely to develop the condition. Consequently, CP prevalence increased towards the end of the 20th century with higher rates of survival amongst preterm infants, but has plateaued in recent decades in high income countries (HIC). The majority of CYP with CP, however, are born full-term (50-60% in high-resource settings, more in under-resourced settings). These cases of CP occur as a result of placental

abnormalities, birth defects, meconium aspiration, instrumental/ emergency Caesarean delivery, neonatal seizures, respiratory distress syndrome, hypoglycaemia or neonatal infection. In HIC, birth asphyxia plays a relatively minor part in overall CP aetiology. In contrast, in lower-resourced settings, birth asphyxia together with low birthweight are the most common risk factors for CP, with kernicterus and neonatal infection also playing an important role. People with CP can face a range of co-morbidities and challenges (Box 1). A systematic review showed high quality evidence of the high prevalence of the following co-morbidities: inability to walk (1 in 3) or talk (1 in 4), epilepsy (1 in 4) or deafness (1 in 25). There was also moderate quality evidence for a high prevalence of: pain (3 in 4), intellectual impairment (1 in 2), hip displacement (1 in 3), behaviour disorder (1 in 4), bladder control problems (1 in 4), dribbling (1 in 5), blindness (1 in 10) and/or being tube-fed (1 in 15). An estimated 50% of CYP with CP meet the diagnostic criteria for a mental health disorder, the most common being Attention Deficit Hyperactivity Disorder. In later life, multi-morbidity for non-communicable diseases is also high, presenting in more than half of all middle-aged adults with CP.

**Box 1. The clinical manifestations of CP**

*The clinical manifestations of CP vary in type of movement disorder, degree of functional ability, and body parts affected<sup>4</sup>. Patterns of motor defects largely depend on the location of the brain lesion underlying the CP. Infants may initially present with feeding difficulties, delays in motor milestones, abnormalities of tone, posture and movement and early hand preference. Severe cases may present soon after birth, whilst milder cases present at 2-3 years of age. A variety of systems of clinical presentation classification exist, including by topographical involvement of limbs (diplegia, quadriplegia, hemiplegia), clinical signs and symptoms (spasticity, dyskinesia, ataxia), functional limitations (e.g. Gross Motor Function Classification System), and resting tone (hypotonic, hypertonic, isotonic).*

*Diagnosis of CP is clinical, based primarily on history and examination, however, it is supported by neuroimaging, such as MRI and cranial ultrasound. Examination of high-risk infants, such as those with a history of prematurity and hypoxia-ischaemia, can be undertaken using procedures such as General Movement Assessment (GMA), which in combination with imaging, can increase the sensitivity and specificity of CP diagnosis within the first year of life.*

CYP with CP often frequent healthcare service users due to health conditions caused directly or indirectly by CP. They often require a range of specialist healthcare services, such as physiotherapy or speech and language therapy. A challenge in providing equitable care for common childhood conditions is lack of knowledge and confidence in management of CP by the primary-healthcare provider, resulting in unnecessary referrals to specialist care, and/or sub-optimal quality of care. It may also be difficult to perform routine health care activities, such as standard dental examinations. Consequently, consideration needs to be given to ensuring that healthcare providers are appropriately skilled in assessment and management of CYP with CP and that facilities, including equipment, are accessible to CYP with CP.

The needs of CYP with CP extend beyond healthcare services. CYP with CP, particularly those with intellectual impairments, may face difficulties in accessing mainstream schooling, resulting in school exclusion or poor educational experiences. However, support through additional assistance in mainstream schools, or inclusion in specialist schools, is available in the UK. CYP with CP often require formal review to access school-based therapy services and appropriate levels of educational support (e.g. Education and Health Care Plans (EHCP) in the UK). Social inclusion in schools also needs to be supported, so that education is not focused on academic achievement alone. As the child transitions into adulthood, their needs will change; in addition to the biological, psychological and emotional impacts of puberty, social issues such as independent or assisted living, developing relationships and inclusion in employment, become more pertinent. These wider impacts will not be the same for all CYP and is not determined only by the person's clinical characteristics, but is also influenced by personal factors (e.g. level of wealth and social support), sociocultural factors, community perspectives and the environment in which he/she lives (e.g. accessibility of physical environment). An example of how these elements may differentially impact a CYP with CP is that of menstrual hygiene.

The impacts of CP extend beyond the child affected to the parent carer. Parent carers experience high levels of physical and mental conditions, which can persist and worsen over time. Furthermore, parent carers report barriers to accessing healthcare and preventive services for themselves, and/or difficulties in engaging in healthy behaviours.<sup>1</sup> Families

report experiencing stigmatising attitudes and discrimination as a result of caring for children with complex neurodisability. They are less likely to be in active employment, and if employed, on average receive lower pay (irrespective of educational level). Caring for a CYP with CP can also impact on parental relationships, including being unable to set aside time for the caregivers themselves and for other members of their families, more frequent arguments with a spouse and higher rates of divorce. Siblings may also be affected, as having a brother or sister with a chronic illness or developmental disability is a risk factor for sibling adjustment problems, particularly in young children: psychological functioning (i.e., depression, anxiety), peer activities, and cognitive development scores were lower for siblings of children with a chronic illness compared to controls.

#### **Current approaches to improving inclusion and quality of life for CYP with CP in the UK.**

CP impacts the individual and their family, often across multiple domains of physical and mental health, educational opportunity and social care. Therefore, a holistic, patient-centred intervention may best meet the needs of CYP with CP and their families.

Recent UK National Institute for Health and Care Excellence (NICE) guidelines emphasise the need to provide clear, timely and up-to-date information to parent carers about CP and supporting services including topics of diagnosis, aetiology, prognosis, expected developmental progress, co-morbidities, available resources, educational provision and transitioning from child to adult services. These guidelines highlight the importance of providing ongoing patient-tailored information and access to local support groups for both CYP and parent carers. However, the guidelines do not identify any evidence-based interventions effective in meeting these needs, or in helping caregivers to navigate services. Furthermore, services designed to meet the medical needs of CYP with CP and the local provision of support and advocacy groups vary in availability and quality across the UK.



In HIC, CYP with complex medical conditions such as CP account for an increasing proportion of public health use and expenditure, particularly relating to services of which they are intensive users (e.g. accident and emergency departments). The UK National Audit Office's report on NHS efficiency savings highlighted the advantages of migrating services from hospitals into the community for patients with long-term conditions (LTC) such as CP. A focus was placed on providing integrated pathways for individuals with LTCs, whereby higher quality, local, more comprehensive community care is provided. The rationale is that these community services will reduce unscheduled acute care by better management to slow condition progression, ensure greater provider efficiency and productive care more generally and to ensure early recognition and intervention in the event of deterioration.

Some evidence exists around the benefits of community-based support for parent carers of CYP with complex needs, which provide learning for the development of interventions for parent carers CYP with CP. For instance, relevant evidence for effectiveness exists across a range of medical conditions around peer-to-peer support, group-based interventions for other LTC and for participatory women's groups in low income countries (LICs) to improve newborn survival and other newborn outcomes. There is also good evidence to support the value of 1:1 peer support with parents of a CYP with an impairment supporting another parent, with cited positive impact on parental psychological wellbeing. A systematic review of community-based peer support interventions (all delivered in HIC settings) for parents of CYP with chronic conditions (not limited to neurodisability) reported that caregivers valued a shared social identity; a sense of belonging and empowerment, learning from others' experience, and the mutual positive impact of supporting others.

National guidance, the policy agenda and the available literature therefore support the rationale for community-based peer support interventions for parent carers of CYP with CP in the UK.

### **Community-based participatory approaches for caregivers of CYP with disabilities**

Regionally in the UK, availability of support services for families with CYP with disabilities varies greatly and although there are pockets of excellence, these are not consistently

delivered. Within the UK, support is available through voluntary sector organisations such as Scope, Cerebra and Contact. These UK-based charities offer support services in the form of online discussion forums, telephone helplines and written information online, with Contact also running a service linking families of children with disabilities. The provision of support groups run by such organisations depends on local factors, such as the presence of a local champion. Informal social media groups, for example on Facebook and Mumsnet, also provide community-level online peer support, although content is not regulated. Programmes have been developed at the international level to provide support for parent carers of CYP with neurodisability, but they have not been implemented at scale in the UK.

A review of the literature and consultation with national and international experts identified four group-based parent carer interventions aimed at improving outcomes for CYP with neurodisability. Three of these are at the development/ pilot phase and are based in HIC settings: two in the UK (*Stepping Stones Triple P (SSTP)* and *Early Positive Approaches to Support (EPAtS)*) and one in Canada/Australia (*Enabling VISion and Growing Expectations (ENVISAGE<sup>1</sup>)*). Trials are underway in LICs for the fourth group-programme identified, namely the *World Health Organisation (WHO) Parent Skills Training Package*, which aims to optimise neurodevelopmental outcomes for CYP with all forms of neurodisability. These programmes are described in detail in Box 2.

**Box 2. Examples of Parent/Carer Support Programmes in HIC**

*Stepping Stones Triple P (SSTP)* is an adaptation of the Triple P parent mediated intervention for early intervention into longitudinal behavioural changes in children with conduct or behavioural disorders. SSTP has been adapted for children under 5 years with a broader range of neurodisability. However, it is still primarily aimed at reducing challenging behaviour, by engaging parent carers in a 9-week level 4 SSTP programme in which they are trained in skills to manage their child’s behaviour, through training days, peer group discussions and tutorials. A randomised control trial is currently underway.

*Early Positive Approaches to Support (EPAtS)* is aimed at delivering packages to parents and carers through educational sessions, in order to reduce the risk of challenging behaviours in children under 5, before the event of a crisis. This programme is being trialed in Kent through the Tizard Centre, through seven, two and a half hour sessions with parent carers,

focusing on issues from working together, looking after yourself, though to responding to challenges.

*Enabling VISION and Growing Expectations (ENVISAGE<sup>1</sup>)* is a parent carer virtual-group intervention being developed in Canada and Australia and works with parents of children with neurodisability to generate new ideas for parenting a CYP with any neurodisability (formerly known as “WOW! Welcome Orientation Workshops”). ENVISAGE will be run through a partnership between CP Support Network (CPSN), Australia, and academic partners and remains under development with results of efficacy awaited. It adopts a virtual-group approach, utilising webinars and online forums. One proposed benefit of this approach is the ability to deliver content in a flexible and reactive way, which may be particularly attractive to parents who are busy and unable to attend meetings. Potential limitations include the lack of face-to-face contact and bonding with other caregivers, and the generic nature of content, which will not address issues specific to types of neurodisability.

The *WHO Parent Skills Training Package<sup>3</sup>* for parent carers of children with developmental disorders aims to equip caregivers with skills to better support their children’s development and learning. It was developed through consultation with experts and parents’ associations across all WHO regions, with support from Autism speaks. The initiative facilitates non-specialist providers (e.g. community health workers) to engage families in activity-based learning through nine group sessions and three home visits. The program focuses on supporting and educating caregivers to use everyday activities and resources to enhance learning and development, and thereby optimise developmental and behavioural outcomes for the CYP. An additional goal is to improve parent carer wellbeing. Trials of efficacy are currently underway<sup>3</sup>. However, this program primarily addresses the developmental aspects of all types of neurodisability and does not include wider issues such as health care access and medical complications, nor does it address parent carer knowledge around specific neurodisabilities. Furthermore, it is dependent on community-based volunteers for delivery, a model that may not be feasible in HIC settings.

Ideally, these programmes would utilise a participatory approach, as outlined in Box 3.

### **Box 3. Value of participatory approaches**

The participation of the target population in the development and implementation of health interventions can increase their feasibility and acceptability. Participation can be ensured via co-design with the target population during intervention conception and implementation (participatory action research or PAR) and with peer-led facilitation. The participatory element generates new innovations by supporting the target populations to interpret, apply, and periodically invent methods to explore their context, deliver solutions and disseminate information. These approaches also allow the target populations to

address issues and needs that relate directly to their environment, rather than driven by perceived needs identified by professionals.

A systematic review of participatory approaches in low resource settings concluded that participatory learning approaches are a cost-effective way to improve newborn and maternal survival. However, a systematic review of participatory approaches by UK public health units found that the evidence in this setting is currently lacking. An example of how participatory approaches have been used in the development of interventions for CYP with neurodisability is the *Early Therapy in Perinatal Stroke* (eTIPS) programme; a therapy-based intervention designed to be delivered by parents at home in the first six months of an infant's life post-stroke. It was developed via a participatory approach which used feedback from focus groups of families of children with CP to prompt iterative revisions of the intervention design, with a pilot study currently underway. Given that many interventions for CP are designed to increase participation of CYP in physical or social activities, participatory approaches could capture the intrinsically valuable voice of this population and optimise the development of interventions for CYP with CP.

There is a variety of community-based support available for parent carers of CYP with neurodisability. However, these supports are chiefly funded by the voluntary sector and dependent on context-specific resources. This suggests that there is a need for a cost-effective, sustainable and participatory community groups that could be funded and regulated by a central body and embedded within the NHS.

#### **Evidence of effective community groups for parents/ carers of CYP with CP from LICs**

To our knowledge, there is no published study examining the clinical and/or cost-effectiveness of group-based interventions for parent carers of CYP with CP that targets improving health and wellbeing of the CYP in the UK, or other similar HIC settings. The four interventions described in Box 2, do not address this gap. Two are aimed at improving challenging behaviours in children under 5 years with neurodisability: *SSTP* and *EPAtS*) A third intervention, *ENVISAGE*, is a virtual group programme aimed at improving parenting skills. The fourth, *WHO Parent Skills Training Package*, focuses on improving parent carer skills around learning and development. Therefore none address the holistic needs of the parent carer and CYP. . There is, however, growing evidence for the effectiveness of a group intervention for parent carers of CYP with CP in LICs (for example the *Getting to know CP* programme). Examples for, and some evidence around, adult focused community groups exist. There is also some evidence for community groups focused on adult outcomes – for adults with CP and for the adult primary carers. Examples of these programmes are provided in Box 4.

#### **Box 4. Community groups for adults with CP and caregivers of CYP with CP**

The *Women's Health Initiative* is an example of a platform/group for women with CP. It aims to transform healthcare for women with disabilities, towards empowering them to expect equal healthcare standards to those received by the wider population, and guidelines for best practice on how to deliver it.

The *Healthy Parent Carers programme (HCP)* has recently been shown to be acceptable and feasible in a UK proof of principle and subsequent feasibility study. It is a peer-led group-based health promotion intervention that encourages engagement in behaviours associated with health and wellbeing<sup>1</sup>. This intervention focuses specifically on the health and wellbeing of the parent carer and does not target issues around the CYP; though having a healthy parent is likely going to benefit their children and families.

Only one group intervention was identified that aimed to improve outcomes for CYP with CP, namely the Getting to Know Cerebral Palsy (G2kCP) programme. The G2kCP programme has been evaluated formally<sup>4</sup> and is being implemented by at least 50 partners. The core aim of the G2kCP intervention is to improve the quality of life for parent carers of CYP with CP by improving their knowledge and skills and providing psychological support through the peer group.

Further down-stream goals of the programme are to maximise the developmental progress of affected CYP and their quality of life, partly by improving the early detection and control of co-morbidities. G2kCP is designed as a community-led and holistic model of healthcare delivery, contrary to top-down health worker-led models. The programme consists of 10 modules delivered in group sessions in the community lasting 2-3 hours, run over a duration of between 3 and 12 months. Groups include 6-10 parent carers, and their CYP with CP. It provides information for caregivers of CYP with CP using participatory methods, in line with priority areas of care identified by NICE guidance, on topics including: positioning and carrying; communication; everyday activities; feeding; playing; disability in the local community and assistive devices.

G2kCP was originally developed in and for rural Bangladeshi communities, through co-production with parent carers of CYP with CP. It has since been adapted and implemented in Uganda (for a younger age group (< 2 year old), randomised control trial underway), evaluated in Ghana<sup>4</sup>. It has also been adapted and piloted in Brazil to support caregivers of infants with Congenital Zika Syndrome. The Ghana impact evaluation documented significant improvements in parental quality of life (as assessed by PedsQL Family Impact Questionnaire) and self-efficacy (defined in this context as 'knowledge and confidence of taking care of the child'). A pre and post evaluation of the early intervention programme in Uganda showed a 25% improvement in quality of life at the level of the family in Kampala.

It is clear that the programme is highly appreciated by parent carers, and relatively low-cost to establish and run. In terms of limitations, few changes have been observed in nutritional or functional status of the children, although the evaluation was not powered to detect these changes, and most of the positive impacts reported are in parent carers' knowledge, mental health and quality of life. It has not yet been used in a HIC. However, there is a strong rationale that this programme would be feasible, appropriate and effective in a UK setting, given that the programme content is in line with NICE and NHS guidelines, would fulfill the reported unmet needs of caregivers of CYP with CP, uses participatory methods, and is likely to be relatively low cost to implement.

## Conclusions

CP is common in the UK and has a broad range of health and other impacts on the wellbeing of CYP with CP and their parent carers. There is evidence for the need to develop an NHS community-led intervention that can support CYP with CP, their parent carers, and potentially alleviate some pressure on disability support services. Participatory approaches and co-production have been the key to a number of highly successful group interventions in LIC settings. Parent carer support programmes, such as *G2kCP*, have been successfully developed and implemented in low and middle-income settings for CYP with CP and with other complex neurodisabilities, working to improve the knowledge and skills of caregivers and have shown positive impact on parent carer wellbeing and knowledge and potential. No such intervention has yet been developed or tested in the UK health care setting. Such a programme could help to realise the rights and fulfill the needs of CYP with CP and their carers, provide psychosocial support to caregivers and help in the care of their child, and consequently optimise the child's overall health and functional status. The first step towards achieving these outcomes would be adaptation of the programme to the UK setting, and testing for acceptability and feasibility within the NHS context and within the target population.

## Practice Points

- CP is the commonest cause of childhood physical disability in the UK, as well as worldwide.
- There are four group-based parents carer interventions at the development/trial phase. Two are aimed at improving challenging behaviours in children under 5 years with neurodisability : *Stepping Stones Triple P (SSTP)* and *Early Positive Approaches to Support (EPAtS)* A third intervention: *Enabling VISION and Growing Expectations (ENVISAGE)* is a virtual group programme aimed at improving parenting skills. The fourth, *WHO Parent Skills Training Package*, focuses on improving parent carer skills around learning and development. Therefore none address the holistic needs of the parent carer and CYP and the closest programme (ENVISAGE) is a virtual parent forum/ network rather than face to face group based programme.

- G2KCP is a carer support programme that uses participatory methods that aims to improve the quality of life of carers and CYP, and the functional status of the CYP. It has been successfully developed and implemented in low and middle-income settings for CYP with CP and is also being developed for CYP with congenital zika syndrome.
- There is a strong rationale that a modified G2kCP programme would be feasible, appropriate and effective in a UK setting. An optimised version of the programme, adapted to the UK setting, and evaluation of acceptability, feasibility and effectiveness in the UK NHS context is needed.

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