

# The Carousel Project

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Provision by Lambeth Mencap  
for people with profound and multiple  
learning disabilities

An independent evaluation report

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**Approved by the Carousel Project Steering Group  
January 2016**



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# 1. Executive Summary

## Introduction

The Carousel Project arose as a direct response to a major need for improved services for people with profound and multiple learning disabilities (PMLD), identified nationally (Mansell, 2010) and locally, in Lambeth (Mencap, 2010). This low incidence population are recognised to experience significant inequalities in the services they receive and are amongst the most isolated and marginalised in modern society, and by default so too are their families. They continue to be a group at high risk of experiencing inadequate and non-personalised services, despite this recognition (Harflett *et al*, 2015).

### Rationale for project

The fundamental premise of the Carousel Project was that by creating local opportunities for people with PMLD to be physically active, intellectually engaged and socially connected, their health and lives would improve. It was also envisaged that indirectly this provision would improve the lives of their family carers. The project aimed overall, to improve access to sustainable local services for people with PMLD from Lambeth.

By gathering the views of a wide range of stakeholders and from direct observations during frequent visits to the Carousel Project activities, there was strong evidence of positive and cumulative change. The evidence demonstrated that this project had not only actively initiated and contributed to improvements for this particular population but also, influenced wider, more universal change.

### Impact of the Carousel Project:

#### For People with PMLD

The people with PMLD were the main benefactors from involvement in this project. Stakeholders unanimously described a range of improvements in the people with PMLD whom they care for and support. These positive differences ranged from the emergence of very small and subtle changes through to transformative and life changing breakthroughs, where one individual was enabled to meaningfully and enjoyably participate in a group opportunity, for the first time in their life.

Families and professionals encouragingly commented on the benefits to people with PMLD, developed over time, from project involvement. At a general level, they highlighted noteworthy improvements to daily life following Carousel Project activities [eg more relaxed limbs and ease of dressing, improved appetite, and improved sleep patterns] which in turn positively influenced their health. Every stakeholder described the influence of the project on overall Quality of Life for these individuals. They identified that for this group, taking part in the regular Carousel Project activities facilitated opportunities to be physically active and for learning, leisure and social engagement that they had not previously experienced. At a very detailed level, professionals and families commented on positive changes and improvements relating to a number of very

relevant issues for people with PMLD; postural care, activity levels, opportunities for communication, levels of engagement, emotional wellbeing and social inclusion were common areas of observed improvement.

### **Wider impact**

In addition to benefits and improvements for individuals with PMLD, the Carousel Project influenced many wider outcomes.

- Families

When considering the health and wellbeing of family carers, the project was working against local limitations. Families from Lambeth reported they experienced a continued shortfall in local respite opportunities, even though their needs for this as Carers were formally identified. Despite this gap in local provision, the Carousel Project was viewed as very beneficial by the family carers involved in this evaluation. The project was not intended to provide a respite service. However, family carers involved in this evaluation stated that they had experienced positive change to their own wellbeing as a direct result of involvement in the Carousel Project.

- An accurate database of the local population

There was initially some discrepancy in accurately recognising individuals with PMLD from the shared Lambeth data who may be eligible to join the Carousel Project programme of activities. More rigorous use of a screening tool to identify people with PMLD was used to develop the Carousel Project database of individuals from Lambeth. Collaborative working with local healthcare trust professionals and comparison to trends in health trust's neighbouring boroughs led to a more accurate picture of actual numbers, from that held by the local authority. It appears the project's current recruitment and growing attendee numbers reflect the local population of people with PMLD.

- The PMLD Sub-group

This group has played a key role for the project. It was initiated by the project manager in response to the identified local need (Mencap, 2010) and before funding for the Carousel Project had been secured. A number of family carers have become actively involved in this group along with a commissioner and other local professionals, service providers and healthcare professionals. Their collaborative work and lobbying has successfully resulted in positive local change, for example influencing the appointment of a specialist physiotherapist for Lambeth. Its role continues to ensure people with PMLD are appropriately a set item on the local agenda and no longer disenfranchised.

- Adding value to local health services

Collaborative working between the Carousel Project and local authority health services have added value to local provision. Reciprocal approaches have led to improved access to specialist healthcare for people with PMLD, new opportunities to monitor individuals between blocks of specialist intervention and new and additional occasions to support and advise carers and support workers in best practice. Many aspects of the Carousel Project activities complement the work of specialist healthcare professionals through for example, increased opportunities to develop communication and interaction and to deliver postural care or

physiotherapy programmes, additional rebound therapy and sessions of swimming in a hydrotherapy pool.

- o Local providers and the wider workforce

Involvement in the Carousel Project proved to be seen to contribute to professional development by support staff, personal assistants, home managers and some student healthcare professionals. Many suggested the Carousel Project staff had provided excellent role models to develop their own skill set when supporting people with PMLD. Some particularly commented on the value of working alongside others, rather than their more usual and often isolating role when supporting an individual as their 1:1 worker. A number of home managers involved in the project described how being motivated and supported by Carousel Project staff had developed the creativity and the confidence of their staff teams, for example to use manual handling equipment, to position people to protect their body-shape or to use specialist approaches to enable people with PMLD [eg Intensive Interaction].

- o Community resources and access

In establishing a core programme of activities in the local community, the Carousel Project has raised awareness of people with PMLD and facilitated many reasonable adjustments to be implemented within and around Lambeth. As the project numbers increase, additional activity sessions have been rolled out maximising the potential impact of improved access. This will benefit the local population beyond the scope of the project.

- o External challenges

There were numerous obstacles in the local environment that created major barriers to the implementation and progress of the project. These included venues that were not accessible for people with PMLD, for example, no Changing Places toilets and a lack of access to use community leisure facilities – for example, no hoists or steps to use trampolines. Public attitudes were also a barrier – for example a lack of awareness and low expectations by some professionals of the potential outcomes for people with PMLD, resulted in very limiting support plans and insufficient budgets.

The full economic costs of supporting the Carousel Project are not currently reflected in personal budgets or individual service funding. Profound and multiple learning disability is a low incidence disability and therefore lacks the economies of scales of larger groups. Sustaining these essential project activities for this otherwise marginalised population, requires an urgent coordinated and collaborative response from local services.

- o An innovative model

This project set out challenging aims and expectations to raise the bar for people with PMLD from Lambeth, acting as their champion. From the outset it assumed a person-centred ethos with high aspirations for every individual involved in its activities. Despite the project facing many setbacks due to deep rooted barriers, there is already a growing body of evidence from those involved, to demonstrate improved health and quality of life for this population.

The unique and innovative model developed by the Carousel Project adopts many of the principles and good practice advocated for coordinated, person-centred services [also described as integrated services]. This particular project and its approaches affords wide ranging potential to influence and improve local service provision - for people with profound and multiple learning disabilities and other marginalised groups. With secure funding, this population from Lambeth will continue to experience the services they need and an improved quality of life.

## 2. Introduction

***From personal observation and attendance with (my daughter) and her companions at many sessions over the last two years, starting with the embryonic Saturday Stories and continuing through Hydrotherapy, Dance & Movement and Rebound Therapy, I am convinced of huge and undeniable transformations in the lives of some Carousel participants, one of whom is about to celebrate her 84<sup>th</sup> birthday!***

Family carer

Introduction to this evaluation report

Initiating, establishing and continuing to develop this ambitious and innovative new project in a two year timescale has presented a diverse range of developments and outcomes – some predictable and others not so! The tasks involved in getting the project onto a sound foundation have created some outcomes that have generated unexpected advantages but others have presented real obstacles and challenges and unavoidably slowed the overall project advancement.

Each small and often testing step of progress achieved by the Carousel Project to develop responsive provision for adults described as having profound and multiple learning disabilities [PMLD] from Lambeth, have without doubt created a better understanding of the very complicated nature of this too often marginalised population. It has revealed insights into the many difficult and complex realities of improving their lives by striving to meet their immediate and longer term needs, locally and in the most appropriate and meaningful ways.

### 2.1 Background to the Carousel Project

The catalyst for the Carousel Project was the Lambeth PMLD Project (Mencap/Lambeth, 2010); research which reported on the incidence, profile of needs and lives of adults with profound and multiple learning disabilities [PMLD], their families and carers from the borough of Lambeth. This 2010 project was initiated by family carer representatives on the Lambeth Learning Disability Partnership Board in response to the paucity of local opportunities and provision for their family members. The findings of this report echoed many aspects of a national review of services for this population, commissioned by the Department of Health (Mansell, 2010).

In his national review, *Raising Our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities* (2010), Professor Jim Mansell reports that despite clear government directives, there were clear inequities experienced by people with PMLD in access to appropriate and responsive services. 'Valuing People Now (Department of Health, 2009) examined progress in implementing

the 2001 White Paper Valuing People: it concluded that, while good progress had been made on many fronts, commissioners and policy makers were not sufficiently addressing the needs of people with learning disabilities who had more complex needs, including people with profound intellectual and multiple disabilities. The strategy was strengthened to ensure that it did address these needs, and this report is part of the process of implementation'. (Mansell, 2010; 2).

The reviews by Mansell (2010) and Mencap (Mencap/Lambeth, 2010), are not alone in highlighting the disparity in access to appropriate provision and services for people with PMLD. A very recent review (Harflett *et al*, 2015) for the National Development Team for Inclusion (NDTi) found evidence from a number of studies to suggest that within the learning disabilities population generally, there were further hardships and inequalities experienced by certain individuals they saw as being adversely 'isolated'. Those perceived in their study to be marginalised were identified by certain characteristic factors, which were also identified in those people taking up Carousel Project involvement in Lambeth.

'...there are some groups of potentially isolated people with learning disabilities who are missing out on personalisation in one or both of two ways: (i) They are less likely to have access to a personalised approach or mechanism in the first place. (ii) If they do have access to a personalised approach or mechanism they are less likely to experience the most positive outcomes from it. The evidence points to at least three potentially isolated groups of people with learning disabilities who may be missing out – those with complex needs, those in residential care or out of area placements, and those without families' (Harflett *et al*, 2015: 5).

Harflett *et al*, clarify those identified with complex needs include people described as having profound and multiple learning disabilities [PMLD]; they specifically include case study examples from this population. Their evidence communicates experiences of inequity, identical to those involved with the Carousel Project.

'...it appears that some of the most isolated people with learning disabilities are less likely to have access to various aspects of personalisation (e.g. personalised care and support plans, personal budgets etc.), less likely to benefit when they do, and less likely to have access to the advocacy needed to address this. As personalisation is a core element of current and future health and social care policy and provision, this raises serious concerns'. (Harflett *et al*, 2015: 9)

## 2.2 Definitions - Setting the context for people with profound and multiple learning disabilities

It is widely acknowledged that there is a group of people with learning disabilities who have a complex range of difficulties which may include:

- profound learning disabilities
- physical disabilities that limit them in undertaking everyday tasks and often restrict mobility
- sensory impairment
- complex health needs, i.e. epilepsy or respiratory problems, eating & drinking problems
- challenging behaviour
- restricted communication, i.e. pre-verbal though a small number have some spoken or signed language

People with these characteristics are described as having profound and multiple learning disabilities (PMLD) (Scottish Government, 2015: 11).

Valuable details about the distinct and complex needs of this low incidence population are described elsewhere, for example <http://www.pmldnetwork.org/>

### **Carousel Project – working definition and the Lambeth context**

People with profound and multiple learning disabilities (PMLD) are among the most disadvantaged in our community.

This group have profound intellectual disabilities, which means their intelligence quotient is estimated to be under 20, with severely limited understanding. In addition they have multiple disabilities, which may include physical/sensory disabilities, and extremely complex health needs, often including:

- Impairments of vision/hearing/movement
- Epilepsy and autism
- Total physical dependency, inefficient posture control
- Risk of body-shape distortion, potentially leading to serious consequences for health and quality of life, even resulting in premature death.
- Susceptibility to conditions such as chest infections and gastro-intestinal problems.
- Dependency on technology, e.g. oxygen, tube-feeding, suctioning equipment.
- Problems of challenging behaviour, (self-injury).
- Complex communication problems, where people may not have reached the stage of using intentional communication, and rely on others to interpret their reactions to events and people.

In 2012 the estimated number of people with PMLD on the Lambeth Learning Disability Register is approximately 85. Of these, it is estimated that about 50 live in the borough, and 35 of these people live in the family home.

Lambeth Mencap (2012)

## 2.3 Project objectives

The Carousel Project proposed to meet the needs of this group in Lambeth through a number of broad objectives outlined to the GSTC funders (Lambeth Mencap, 2012)

By providing access to increased levels of physical exercise and activities, the objectives of the project and the changes we expect to see are:

1. Improved access to sustainable services for people with PMLD
2. Health improvements for people with PMLD
3. Health Improvements for Family Carers of people with PMLD

## 2.4 Health and wellbeing in people with PMLD and the Lambeth context

In recent years an increasing body of information confirms the differences of health outcomes and mortality rates of people with learning disabilities compared to the general population (for example, Heslop *et al*, 2013; Public Health England, 2014). This data concludes that people with learning disabilities have poorer health and die younger than the general population and more specifically, the focus of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities [CIPOLD] found a significance relating to deaths in people with PMLD. 'Compared with national data, our cohort is over-represented by those with severe or profound and multiple learning disabilities among both adults and children'. (Heslop *et al*, 2013:26).

Public Health England (2014) report that many of the differences in health statuses people with learning disabilities experience are, to an extent, avoidable or have the potential of being more effectively treated. Common health problems they identify include:

- Physical impairment with associated risk of postural distortion, hip dislocation, chest infections, eating and swallowing problems, gastro-oesophageal reflux, constipation and incontinence
- Epilepsy
- Sensory impairments
- Mental health problems (including dementia)
- Respiratory disease
- Coronary heart disease
- Underweight
- Obesity

Data gathered at the start of the Carousel Project identified those people with PMLD from Lambeth involved in the project at that time experienced many of these long term health issues and carers reported that some of these conditions were not being addressed adequately by health services, if at all [Interim Report, 2014].

As a response to the clear inequities of health outcomes for the general learning disabilities population, the Health Equalities Framework [HEF] was developed

(UK Learning Disability Consultant Nurse Network, 2013). This reflective tool provided a process of systematic review by which to measure progress and judge access and provision against a set of determinants from both practitioner and service commissioner perspectives.

Of particular value to this review, the five broad determinants identified by the HEF provide a clear match to areas also of concern to the Carousel Project in its consideration of potential for improvement and change.

The HEF Framework determinants;

- Social determinants of poor health [including social disconnectedness]
- Biological determinants of physical and mental ill health related to learning disability
- Communication difficulties and reduced health literacy
- Personal health behaviour and lifestyle risks [including physical activity and exercise]
- Deficiencies in access to the quality of healthcare and other service provision

Reference to this framework is made later, to reflect on the findings of the evaluation process.

## 2.5 Wellbeing

Quality of life [QOL] is influenced by more than good health or simply the absence of poor health. Indicators of QOL may suggest many determinants but all include factors that impact on positive emotional and mental health and general wellbeing. Where people live, and their access to services is just one clear influence to the health and lives of its population. Of note for this research, HSCIC (2015) measured 'the overall social care-related quality of life (SCRQoL) ... [across] England in 2014-15 ... the London region has the lowest outcome'. Of importance to this review is the significance of a sense of general wellbeing to the improved quality of life for people with PMLD from Lambeth.

The Care Act 2014 adopts a 'principled approach' to adult social care, detailing from the outset that 'the general duty of a local authority... in the case of an individual, is to promote that individual's wellbeing' (section 1:1). Broach (2015) offers the interpretation that this duty involves 'local authorities *actively seeking to improve the wellbeing of disabled people and carers in everything they do under the Care Act*'.

The act defines 'wellbeing' in relation to any of the following:

- a) personal dignity (including treatment of the individual with respect);
- b) physical and mental health and emotional wellbeing;
- c) protection from abuse and neglect;

- d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);
- e) participation in work, education, training or recreation;
- f) social and economic wellbeing;
- g) domestic, family and personal relationships;
- h) suitability of living accommodation;
- i) the individual's contribution to society.

(Section 1:2)

Many of these aspects of wellbeing have particular implications when considering indications of improved life for those people with PMLD involved with the Carousel Project. Perhaps those most noteworthy here, would include issues and evidence of change relating to - personal dignity; physical and mental health and emotional wellbeing; control by the individual over day-to-day life (including over care and support...); participation in ... education, training or recreation; social and economic wellbeing; domestic, family and personal relationships.

Also of note for this evaluation, is the entitlement for carers, set out by the Care Act 2014, for their own needs and wellbeing to be addressed by local authorities.

#### People with PMLD and the Lambeth context

Information collected from a small but significant number of individuals at the start of the project, offered invaluable insights into the complex needs and lives of people with PMLD from Lambeth and their family carers [Interim Report, 2014]. For many participating in this information sharing, it was clear their lives continued to reflect the ongoing support and care needs of their lifelong disabilities and health conditions against clear shortfalls of provision and opportunities (as reported in the 2010 research by Mencap/Lambeth).

### **3. Gathering data for this evaluation.**

The main purpose of this review was to seek evidence of change arising from involvement in the Carousel Project for individuals with PMLD from Lambeth. However it also examined a number of the wider implications arising from the project in order to gain some insight into potential influences to further improve the lives of these people in the future.

The review considered the overall progress and development of the project by the end of the GSTC funded phase and included, for example, issues relating to

- the accuracy of local data
- project recruitment, attendance and retention
- access in the local community - suitable community venues, transport, specialist facilities and reasonable adjustments
- developing a programme of appropriate and meaningful activities
- collaborative approaches
- reaching and supporting carers
- access to information and advice
- support and the wider workforce
- training and support
- the profile of people with PMLD by service providers

Stakeholder views of the Carousel Project and its influences:

Information and feedback from a variety of stakeholders was collected from the outset of this two year project and then, at agreed intervals, across the project duration (largely as proposed).

Some variations from the original evaluation phases were directed by the Project Managers, to meet needs and changes arising as the project progressed. For example, there were significant delays early in the project in creating the database of the local population. This was due to unexpected difficulties in accurately identifying the adults with PMLD from Lambeth.

#### **3.1 Initial data**

As a consequence of the delayed timeline, it was decided to extend the initial baseline survey of family carers to include the more detailed information gathering, originally planned for the second phase of the evaluation process. Attempts were made to make direct personal contact with carers of every one of the 34 people with PMLD identified on the project database, to request their involvement, to explain the purpose of this data collection and to seek their preferences to a face to face interview or a postal questionnaire. Not all carers were reached. As a consequence, postal questionnaires were sent to 19 carers, whilst 15 carers opted for a preference to complete theirs through face to face interviews in family homes. Despite great efforts to be flexible in interview arrangements it was not possible to complete a number of these. Final completion rates were lower with 4 returned by post and 8 through interview; overall 12 completions from the total sample of 34.

This research, involving family and paid carers generated valuable, broader information about the complex personal profiles of need for individuals against broad descriptions of PMLD. The data also provided a more holistic picture of life for these individuals early in their involvement with the Carousel project. Carers gave evidence and views, sometimes in the form of ratings:

- status of health and wellbeing (and incidence of unplanned hospital treatments over that year)
- access to general health services (including evidence eg annual health checks, health action plans)
- advice and support for postural care and mobility (including current opportunities for physical activity)
- opportunities for local day time activities
- local opportunities for socialising and information about personal funding and support planning (including evidence of person centred plans, communication passports etc.)
- access to information support and advice.

Those who were family carers commented on the impact of their carer role on their own health and wellbeing, and particularly how services responded to their needs, for example through access to support and respite services. The combined data and review informed the Interim Report (2014).

The stakeholders

It was not straightforward to gather the 'authentic views' directly from the individuals with PMLD themselves, due to their severe communication difficulties. As a response to this the evaluation actively sought the observations of others who knew these individuals very well. They shared their interpretations of Carousel participants' unique responses and participation in the project and their own views of possible changes to any aspect of their lives.

### **3.2 The final phase of evaluation**

This final phase invited the views of involved stakeholders comprising family members, paid carers and support workers, allied health professionals, Carousel Project staff and others who had direct involvement with the project or its activities [including for example, voluntary organisations and student physiotherapists].

Those offering consent to participate were approached directly to gain their views. This feedback was collected using a number of routes to respond to the preferences of individuals and included face to face interviews, telephone interviews and email communication [using the same open-ended question structures]. Follow up communication took place in some cases, to ask for clarification or where respondents offered further exemplification. Some individuals also shared third party information, for example following their attendance at relevant meetings, other discussion forums and testimonials.

Stakeholder role	Number directly approached	Number of respondents	Type of feedback from respondents
Family carers	8	5	Face to face interviews and Email
Professionals : support/social care	9	9	Face to face interviews and Testimonials
Professionals: healthcare & voluntary organisations	6	3	Face to face interviews, Email, phone interviews or Testimonials
Carousel team	4	4	Face to face interviews, Email, phone interviews
<b>Totals</b>	<b>27</b>	<b>21</b>	<b>33</b> separate sets of feedback

**Table 1: Stakeholder groups for final data collection and review**

### 3.3 Wider information gathering

In order to substantiate the views of stakeholders and to set them within a meaningful context, it was important to review the project from different perspectives and through differing approaches. Project progress and general review was discussed with each of the Project managers at intervals across the project phases. These discussions identified issues that had both promoted and delayed the development of this initiative in achieving the milestones and timescales proposed to the GSTC funders. During these two-way discussions, many ideas were exchanged to influence and resolve project developments and ultimately its progress.

Additional evidence for this review was gathered from the scrutiny of project-related documentation shared by the project team including for example, project planning and review information, meeting minutes, project marketing information, project programme, activity descriptions and sessional records. Consideration was also given to available online local authority data and information from the public domain.

As part of the evaluation process, the researcher visited the Carousel Project core activities on a number of occasions across the two year period to corroborate the information shared by stakeholders and to evidence project developments first hand. Observations were undertaken during the activities of both the project approaches and of the responses and levels of engagement of people with PMLD. Researcher interpretations were further substantiated through discussion with stakeholders in attendance, followed up with the project team or validated from documentation at a later stage.

### 3.4 Assuring quality in the review.

This ongoing cycle of review which adopted diversity in its approaches and its data format, offered valuable methods to analyse, interpret and validate the more subjective, qualitative data from stakeholders and beneficiaries. Rose (2014) suggests to be assured of validity when considering such data, qualitative research should substitute the term 'reliability' with 'dependability' but also ensure that adequate tests of 'trustworthiness' are employed.

This view is of particular note for the Carousel Project review, where because of the nature and uniqueness of this population, we cannot look for absolutes or truths. We cannot objectively control variables or their degree of influence on any person with PMLD, but we can ascertain the trustworthiness of our findings by acknowledging these variables and their idiosyncrasies alongside other significant factors of influence. A major challenge to this stance is the very changeable and complex nature of PMLD because of the multi-faceted and pervading impact and influence of this disability.

Further reflection of neutral measures – against independent objective indicators

Broad consideration was given to the findings discussed, with particular reference to externally identified indicators of quality of life [QOL] and determinants of health inequalities to ascertain the validity of those themes identified within the feedback from stakeholders during the project review.

Recognised QOL domains relating to both ‘mainstream’ [EQ5D] and specialist perspectives [QOD-PMD] were deliberated. The latter tool is very specific to the population of people with PMLD and has been developed and rigorously validated within this field (Petry *et al*, 2009). Additional regard was given to an externally accepted overview of health inequality determinants for people with learning disabilities [HEF]. This tool, discussed earlier in this report, was developed by a specialist learning disabilities nursing body as a framework to specifically identify and measure responses to inequities of access to quality healthcare experienced by the wider learning disabilities population and their families and carers.

Overview of the external indicators broadly considered:

<p><i>EQ5D</i></p> <ol style="list-style-type: none"> <li>1. <i>mobility (access)</i></li> <li>2. <i>self-care</i></li> <li>3. <i>usual activities</i></li> <li>4. <i>pain /discomfort</i></li> <li>5. <i>anxiety, depression</i></li> </ol> <p>EuroQol Research Foundation (2015)</p>	<p><i>QOL-PMD</i></p> <ol style="list-style-type: none"> <li>1. <i>material wellbeing</i></li> <li>2. <i>physical wellbeing</i></li> <li>3. <i>social wellbeing</i></li> <li>4. <i>communication and influences</i></li> <li>5. <i>development (opportunities)</i></li> <li>6. <i>activities</i></li> </ol> <p>Petry <i>et al</i> (2009)</p>
<p><i>Health Equalities Framework [HEF]</i></p> <ol style="list-style-type: none"> <li>1. <i>social determinants</i></li> <li>2. <i>biological determinants</i></li> <li>3. <i>communication difficulties and health literacy</i></li> <li>4. <i>personal health and lifestyle risks</i></li> <li>5. <i>deficiencies in access to quality of healthcare and services</i></li> </ol> <p>UK Learning Disability Consultant Nurse Network (2013)</p>	

**Table 2: External frameworks as neutral indicators for consideration**

All items included within these external measures related to six broad themes identified through the evaluation analysis. This secondary stage of review supported and strengthened the dependability of the process and interpretations of the evident themes arising from the stakeholder views.

The perceived value of further consideration, using these external tools as markers of dependability and worth, continues elsewhere within the project evaluation. This additional reflection of the data against external indicators offered confirmation of their value as meaningful indications of change and sometimes, clear improvement to the lives of the individuals with PMLD participating in the Carousel Project activities.

## **4. Understanding the nature of profound and multiple learning disabilities – the challenge of measuring ‘progress’, improvement and change.**

When considering the views and evidence from stakeholders involved in the Carousel project as a measure of the project's success, we must from the outset be mindful of the very concept and nature of progress and improvement in any person with PMLD. The profile of people included within this low incidence group in itself, denotes that any potential indicators perceived as change are all relative to that one person and that their very unique individual strengths and needs in addition to contextual factors will present as influential variables at any given time.

It is accepted that these individuals will present very substantial and global developmental delay and that as a consequence of very severe or profound intellectual impairment, their understanding of the world is through their senses and physical actions and experiences; many of these actions may not be intentional. (E.g. definitions from WHO, 1992; PMLDnetwork, (nd); Scottish Government, 2015). Those described as having profound and multiple learning disabilities experience poor short term memory, possibly influenced by the delay or disruptions (and sometime absence) in establishing neural pathways. As a consequence it could be considered that without sufficient opportunity to develop familiarity or adequate structure and routine to develop anticipation and prediction, even daily life events for these individuals, may appear as if brand new, each time they present – and imagine how anxiety creating that may be.

### **4.1 Recognising ‘progress’**

There is a paucity of literature and research around the broad nature of progress and potential for achieving developmental improvement or change amongst adults described as having PMLD. However a wider scoping identifies valuable sources with a focus on a younger group of the same population [children and young people]. These sources, which include government guidance [e.g. QCDA, 2011; QCA, 2009; Fergusson and Byers, 2015; Fergusson *et al*, 2015a; Fergusson *et al*, 2015b], present some useful insights when considering how to attempt to acknowledge and measure progress and change when evaluating the outcomes of this project within the growing number of adults with PMLD taking part in the Carousel project.

What does progress look like? What might indicate positive change or improvement?

It is of particular significance to consider that progress and whatever may constitute increments of achievement or enrichment for this population is rarely

straightforward and we need to adopt a holistic and multi-dimensional view. Demonstrating steps of movement on any hierarchical framework of 'progress' is likely to be very slow for these individuals, by the nature of their disability, and in some cases rarely exists, where the apparent development of skills and understanding have plateaued. Some individuals may remain on the same key skills and developmental milestones for much or all of their lives. However, that is not to say they are not able to achieve or improve and make genuine 'progress'. But rather it is *how* we view this improvement and change that needs to alter. It is vital we take a wider view of '*what progress looks like*' in order to value and recognise change, however small or subtle -this may constitute very significant achievement and improvement for an individual with PMLD.

Progress might be that a person demonstrates the same skill but with less support or in new situations (a different person, with a different song or in another activity session). It may be they use the skill with greater independence or confidence or their level of engagement or participation is improved either in duration or in degree of involvement. For a number of people with PMLD (particularly those with life-limiting conditions or during episodes of poor health or medication changes) we know that 'remaining in the same place' and maintaining their skills and abilities is actually a measure of authentic progress (Fergusson and Byers, 2015a; QCDA, 2011)

When considering the views of stakeholders as to what they perceived to be benefits and improvements we need to have clear regard to this context for profound and multiple learning disabilities. People with PMLD are likely to demonstrate fluctuating levels of arousal and inconsistent responding – sometimes due to the unfamiliarity of situations or people or due to processing disruptions as a consequence of discomfort or pain, changes in health status or drug regimes. Sometimes responses reflect that the focus of the activity or the particular music or resource used is, or is not, meaningful or motivating for an individual *on that particular day*. For an illustration of such evidence, see Clive's story, Case Study 1.

As a consequence of this conundrum, there is a strong case to make judgements on improvement and change by building a picture of the individual *over time*, in a variety of situations and involving all those who know the individual best (Goldbart, 2015). This approach will not create a 'definitive' measure or judgement, but more valuably provide a better understanding of what uniquely constitutes progress and improvement for that one person.

## Case Study 1: Observations of progress in an individual with PMLD

### **Clive's story: moved by music - an unexpected response!**

Clive, (I was told earlier in my visit), prefers to sit on the periphery of the Carousel activities. Not too close to anyone and just apart from the 'busy-ness' of the activity itself; any closer and he became distressed. He was seated on the edge of the group circle in a large and supportive specialist armchair, his head back and with eyes closed, very relaxed but holding tightly to a blanket. I was unaware of Clive's use of vision or hearing as he remained quiet and fairly passive; he appeared unaware of the sometimes boisterous stimulation of the multi-sensory storytelling in close proximity.

On this occasion of the Saturday Story session it was the week before Christmas and the Carousel staff had introduced some new and festive music to their familiar story routine. One of these was *Fairy-tale Of New York* by the Pogues – an upbeat Christmas song. Suddenly, of his own volition, Clive began to wave one of his arms in the air - almost in time with the music – his eyes wide open and with a facial expression changed to alertness; although not actually smiling he appeared to show a lighter mood. Even to me, someone who didn't know him, it looked as if Clive was completely enjoying this music. At one point he stretched one leg out from under the blanket and it bobbed a little too.

I caught the eye of his support worker and we exchanged smiles, jointly acknowledging that this was indeed a significant moment! This man was clearly engaged at that moment and with that particular piece of music. He was expressing some feelings about the music – it was obviously more than an indication simply of his awareness, (which apparently was a more common response for Clive).

Once the tune ended and the activity had moved on, Clive reverted to his more usual still and calm appearance, eyes closed again. It was not apparent if he was still engaged or interested as the activity continued.

Later, his support worker and I shared the excitement of this significant achievement. He was fairly new to supporting Clive and this was the first time he had seen such an overt and strong response from Clive – to anything. He described how Clive was usually very 'hard to reach', very hard to engage and it was even harder to understand anything that might have a motivating effect for him.

This support worker planned to find the Pogues tune on YouTube and play it again to Clive as soon as they got back home!

## 5. The findings of this evaluation

Stakeholder views on the Carousel Project activities and approaches:

Much of the data gathered for this evaluation was of a qualitative nature, particularly from the latter phases of the project evaluation. A thematic analysis was used initially across all evidence of personal views and feedback after identifying common topics. As a secondary stage, broad reference to certain external domains and indicators of Quality of Life ((QOL-PMD) Petry *et al*, 2009; (EQ5D) EuroQol Research Foundation , 2015) and determinants of health inequalities (HEF), (UK Learning Disability Consultant Nurse Network, 2013) provided additional perspectives by which to consider data .

Stakeholders were asked for their views of the project activities from two perspectives.

- 1: The perceived involvement and responses of the person with PMLD who they support and care for in Carousel activities and, in particular any change or differences noted following participation in these activities;
- 2: Their own involvement in the project and how this may have had any direct or indirect impact or influence on them (as family or paid carers and professionals) including their views on the project approaches.

The findings relating to the first focus [5:1], about the individuals involved in Carousel activities are discussed in the following section; the findings of the second focus [5:2], explore the wider influences of the project and are addressed and embedded within the subsequent discussions.

### 5.1 Views about the people with PMLD participating in Carousel activities

Every participant response was examined on multiple occasions to identify common themes and patterns. Six broad and often overlapping themes arose across this data set, relating to the people with PMLD. These were considered against external frameworks to assure the issues were of relevance to this evaluation. Each of the six themes identified mapped easily to those encompassed within the health and quality of life domains frameworks discussed earlier [EQ5D, QOL-PMD and HEF].

- i. Postural care – including physio programmes and advice, positioning and physical management
- ii. Activity levels – including physical activity and movement opportunities, motor skill development, range of movement and flexibility and general mobility
- iii. Opportunities for communication - including opportunities to respond to sensory stimuli, to communicate preferences and choices, interaction with others etc.

- iv. Levels of engagement – including interest, understanding, anticipation, participation [prompted or otherwise]
- v. Emotional wellbeing – including mood/emotions and their influences on levels of interaction or engagement with activity or others, health related indicators
- vi. Social inclusion – including recognition /familiarity of other people, working and interacting with others, feeling supported , having peers and ‘being part of a group’

Every respondent participating in the evaluation process commented on the very positive outcomes for the people with PMLD they supported or observed in any or all of the Carousel Project activities. These views and comments are explored by topic within a general discussion here. See Appendix 2 for a selection of illustrative examples gathered from the final review process evidencing wide ranging improvements and changes in Carousel Project attendees

### **5.1.i Postural care**

The impact of physical activity, postural care and protected body-shape on the more general health and wellbeing of people is well known and in particular for the PMLD population (e.g. Mansell, 2010; Postural Care Action Group, 2011; Pawlyn, 2013 and Pawlyn and Carnaby, 2008).

All of the people involved in the Carousel activities had considerable needs relating to postural care and physical functioning and very often, additional issues of comfort or physical access to their environment. Many of these people were wheelchair–users and dependent on others to move and re-position them, in order to protect their body shape and maintain their range of movement.

Without exception, every respondent [family and paid support workers, Carousel project staff and allied health professionals] commented positively on the evidence of improvement within this area, directly observed from opportunities created by the Carousel activities. Many also offered observations of changes beyond the activities; some skills were seen to be very positively transferred to other contexts. Personnel from GSTT health highlighted the far reaching and positive influences on health that their interventions afforded by involvement in the project.

## Case Study 2: Healthcare professional reflections

A local healthcare professional comments on the opportunities for health improvement created by the Carousel Project activities:

*'The maintenance of mobility, posture, range of movement, and respiratory status are just some of the benefits of these sessions which have a significant impact on peoples' health needs.*

*The introduction of the trampolining/rebound sessions by Carousel Project also offers a meaningful physical activity in a format that can provide physical health benefits for people who would not access other sessions within a public leisure centre. Alongside this the trampolining/rebound sessions can also be used to address sensory, engagement, and communication needs.*

*The provision of this service is an important step towards addressing physical activity for healthy lifestyles within this population, to promote equity and reasonable adjustment in physical activity provision'.*

### 5.1.ii Activity levels

Respondents offered a wealth of evidence from their observations of improved levels of movement, range of movement and physical activity. Many importantly noted markedly improved levels of confidence in using physical skills and mobility. Almost all respondents gave concrete examples of improvements and likely impact being demonstrated beyond the activity sessions – some reported much broader influences of change.

One support worker gives an overview of the improvements for the person she supports in his own home.

### Case Study 3: Improvements observed by a support worker

Natalie noticed changes in Giuseppe, the young man she supports

When Natalie was asked if she had noticed any changes from what was 'usual' for Giuseppe after he had taken part in Carousel activities, she gave many examples of improvements that she had seen when supporting him in his home;

- limbs more relaxed and overall he was easier to move
- easier to dress after the activity
- more active than usual
- better posture
- more coordinated movements - reaching, grasping items and recently the new skill of transferring and using two hands together
- increased communication in the sessions - more expressive, trying and using different ways of communicating
- happier mood and more alert
- sleep improved
- better appetite

Natalie noticed some of these differences during or straight after the activity sessions, some later the same day and some changes were observed over time.

#### 5.1.iii Opportunities for communication

Thurman (2011) highlights the significance of communication as a fundamental human right for the population of people with profound and multiple learning disabilities – and a right that we need to respect and respond to. She suggests

*'Communication underpins so many of the things that make our lives enjoyable and fulfilling. Communication is important in enjoying life, in expressing what you want and don't want, in expressing who you are and in making relationships: It is vital to making others responsive to your needs and in order to be shown respect and treated with dignity. It is not therefore surprising that in many of the reports where services for people with learning disabilities have been criticised, the topic of poor communication has been highlighted again and again'.(p12)*

Many participants remarked how over time there was a noticeable relationship between the individuals with PMLD appearing more relaxed, becoming familiar with people, anticipating activity routines and these peoples' growing confidence and increased attempts to communicate. Some individuals appeared to be developing *intentional* communication, as they were experiencing opportunities where they had a clear need and desire to communicate and importantly, a

responsive communication partner. Thurman supports this finding, suggesting that for those with PMLD, *'People ... will always remain the most important communication resource'*.

Every respondent shared observations and evidence of positive and significant communicative responses and indications, both during Carousel activity sessions and in other settings. The activities provided a motivating context for many, for example as these comments demonstrate.

Speech and Language Therapist observation during a Carousel activity (via support worker feedback): *'(he) is more communicative here than anywhere else'*

Family carer: shared her excitement about her daughter communicating to others her enjoyment at being on the trampoline for Rebound Therapy with the Carousel staff – *'(she) likes being with people – gives you 'that expression' – tries to call me - to see what she is liking'*

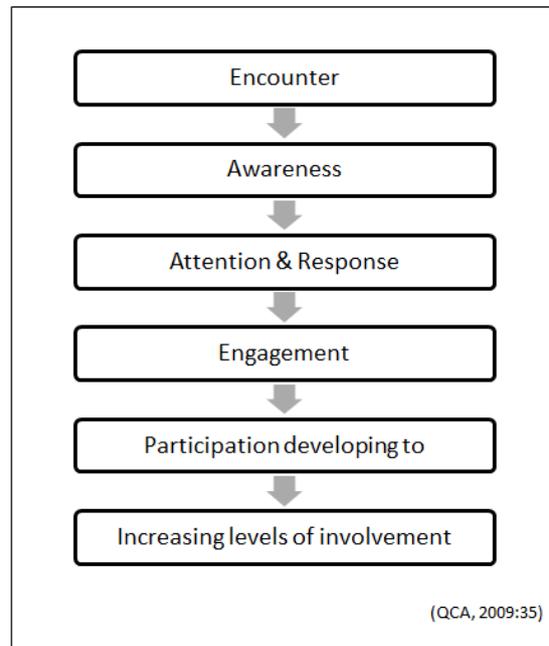
#### **5.1.iv Levels of engagement**

Many of those attending Carousel sessions are not easy to include in any activity in a meaningful or enjoyable way. It is often very difficult to gain their attention or to rouse their interest in any stimulus or for them to become more aware of and make sense of the world around them. We heard numerous accounts of these individuals generally having low states of arousal and often 'falling asleep' - sometimes as a result of medication or simple fatigue from physical effort, but also as a form of 'disengagement'.

It is accepted that many individuals with PMLD require high levels of support and co-active approaches in order to develop participation in many aspects of their lives. As a consequence of this, for some, indications of progress and improvement may be evidenced by a raised state of awareness or attention, by needing less support or observing qualitatively greater levels of involvement and participation.

Every respondent provided examples of positive gains they had observed in the people with PMLD. For some individuals the changes were very tiny steps or subtle changes but for one or two others, those signs of engagement were still yet to emerge.

A framework to recognise progress, drawn from government guidance in the field of education (QCA/DFEE, 2009), may offer helpful measures for reflection by this project. This framework proposes a continuum recognising broad levels of engagement for those individuals with PMLD, who are functioning at the earliest stages of learning:



This inclusive continuum begins with 'Encounter', where an individual is simply 'present' in the activity or experience, often with little or purely reflexive behaviours visible despite full physical prompting and support. It continues through to full levels of participation and true involvement which give an indication of a sound foundation for the next stages of actual skill development. Valuably this framework enables us to observe different levels of engagement across a variety of contexts, which in turn enables reflective practitioners to identify the factors that may influence greater levels of engagement and response from the person with PMLD.

Discussions with Carousel project staff highlighted some Carousel attendees who have been consistently challenging to engage in any meaningful way and appear to remain at the 'encounter' stage within the activities they attend, *'we try really hard to involve her ...but only on her terms'*; *'(he) regularly refuses engagement but we continue to reflect on that – how to reach him – how to include him'*. See the earlier story of Clive, Case Study 1, as an illustration of the challenge of engagement.

Another member of the Carousel team shared the sequence of developing engagement and interest of a young man who was often hard to involve. Once they had identified his growing interest in playing with textured balls they used these as motivators in different Carousel activities - the swimming pool, the dance and movement sessions and Saturday Stories. Offering him a selection of balls encouraged him to sit up from a supine position and to reach for the balls, to choose the ball he wanted to explore. Motivated by the differences in texture, colour and weight he was led to transfer balls from one hand to the other [observed for the first time recently]. Another time he raised himself to a sitting position to reach the balls and for the first time he allowed a Carousel volunteer to massage his back – he enjoyed this too, which then encouraged him to sit up for even longer.

### 5.1.v Emotional wellbeing

Positive mental health and emotional wellbeing is a vital area that permeates and influences every aspect of life. Being aware and responding to changes from what is perceived to be 'usual' for an individual in this area can be challenging, even to those experienced professionals with expertise – more especially in those with profound and multiple learning disabilities, where indications of change or even distress may be hard to perceive and interpret (Fergusson *et al*, 2015; Fergusson *et al*, 2008). Fergusson *et al* (2008) continue to clarify and emphasise the great importance of promoting positive mental health and wellbeing, citing Emerson and Hatton's research which reports the incidence of mental health problems in those with learning disabilities are six times more likely than their non-disabled peers.

Involvement in the Carousel activities (and in life more generally) is most beneficial when an individual is relaxed and calm in order to be 'comfortable', alert and receptive to the world around them. Physical comfort is one major influence on emotional state (no distraction from possible pain or discomfort); the pervading unpredictability of the world around the person with PMLD is also central.

This review evidence demanded two way examination with this crucial focus on wellbeing in mind. Demonstrations of emotional wellbeing - positive or otherwise, as well as being expressions about a person's current status (both physical and psychological), can also offer some key indications as to the appropriateness and effectiveness of intervention, approaches, settings and the specific support in place for the person with PMLD. For these reasons, this area was of particular significance to this review.

The people with PMLD involved in the Carousel Project expressed their emotions and anxiety levels by many non-verbal means – some very subtle, for example 'opting out' of engagement and interaction by not responding or turning their eyes away; some by more overt expressions like ending the activity, leaving the room or becoming distressed. However other modes of expression were also observed for example, where levels of confidence could be interpreted as a demonstration of a person's general emotional wellbeing and trust. A heightened awareness and learning from expressions of emotional state by these individuals enabled the Carousel staff (and others) to be more responsive in meeting very individual needs on a day by day or even minute by minute basis.

Respondents sharing their feedback unanimously offered positive examples of change and improvement to the overall emotional wellbeing of those taking part in the Carousel activities. They offered, some clear examples of decreased anxieties and increased ability 'to cope' with environmental and other stimuli, to more general comments, such as evidence of being more relaxed or seeing the satisfaction and enjoyment from their involvement in the activity sessions. Some attendees showed great strides of progress in a short period of time, but for most the rates of change evolved very gradually over time – for example, shown by the two observations shared here;

One support worker noticed huge improvements after only 5 weeks of attending the swimming sessions, *'see a difference already ... more relaxed ... much happier when the activity starts – gets agitated on the way here ... 100% calm – it's great!'*

As a contrast another support worker talked about the gradual change he had noticed developing over almost two years of attending the Saturday Stories session, *'from time to time she would express excitement ... the big transformation ... happened only recently... when (she)started to fully enjoy the sessions. She gets excited when we talk about going to Carousel'*

#### **5.1.vi Social inclusion**

*Valuing People Now* (Department of Health, 2009) acknowledged that 'people with more complex needs are often not connected to their communities'. This was reinforced by the Carousel Project families when they talked about the high risk of social isolation experienced by their relatives. Early in the Carousel project, 12 family carers were asked directly about the social networks and other social opportunities for their family member with PMLD. Asked if this person had *'an active and meaningful social life ...with opportunities to meet people regularly'*, only 2 of 12 people responded positively, and only then selecting the *'mostly agree'* option. All twelve of these family carers offered suggestions of how this could and needed to improve. [Interim Report, 2014]

Whilst the notion of friendships for people with PMLD may present a challenging concept to address, the literature does offer glimmers of hope that this population do not lead entirely friendless lives. Parry-Hughes (2011) cites research by Emerson and Hatton reporting only 38% of adults with PMLD saw a friend at least once a year, compared to 66% of those for all adults with a learning disability and 92% for the UK population in general. However, quality of life is influenced not solely by friendships but by all relationships and the essential opportunities and right support to develop these essential social connections (e.g. Gurney, 2011; Mattingley and Swift, 2009). The Scottish Government's current strategy for improving the lives of people with learning disabilities emphasises the value in the role of community through the development of *'communities ... opportunities for inclusion and participation will enable people with learning disabilities to be better connected and in control'* (Scottish Government, 2015:10). They cite the added value acknowledged by McLean and McNeice (2012) who purport *'The collective resources that individuals and communities have can protect and develop wellbeing and resilience'*.

This topic generated the greatest number of responses from the overall total of views expressed. There was an overwhelming acceptance that relationships were vital, that being socially connected, more so within the local community, was of crucial importance to the people with PMLD taking part in Carousel activities. It was explicit that whilst *'being out in the community'* and even *'out of the house'* was a distinct need Carousel activities fulfilled for this population, the role it played in creating opportunities and facilitating relationship building and community connectedness was of greater magnitude. Many views of the wider community described the many attitudinal and physical barriers of being included, leading to the person with PMLD being isolated in a community where they were not always welcomed.

The Carousel Project Manager stated that a central role of the project was to facilitate greater inclusion in the local community, *'very important the project has a visibility'*. As people with PMLD gained greater access to their local world,

so they raised awareness of their presence, as part of Lambeth's community and offering their valuable social contribution.

All the views shared reinforced the value placed on relationships and social connections. Interestingly, feedback relating to the social inclusion theme displayed explicit subjectivity; seemingly mutual satisfaction was created by involvement in the Carousel Project. The following examples illustrate these emotions;

A family carer saw the activities for his older brother as a *'chance to make new friends...good to meet people - and people like him'*

Support worker: *'it's lovely to see people happy ... (I get) real satisfaction from seeing (person he supports) with others and so happy – even the bus here is important ...all the chatter together on the way here ... all part of it'*

Support worker: *'(she) enjoys her little circle of friends ... delighted to see a "chatterbox" emerging from someone as shy as (her)'*

Carousel staff: when talking about the time and skill it takes to develop meaningful relationships for the people with PMLD - 'skills of social interaction with others isn't incidental - development of (the) session – try to develop the number of people they (carousel attendees) interact with and trust'.

## **5.2 Exploring the wider influences of the project**

### **5.2 i Information about the local population.**

Accurate data is essential to ensure services can, and do, respond appropriately to the needs of their local population. For people with PMLD and their families, these services will directly impact on the quality and longevity of their lives. Mansell's 2010 report affirms: *"Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected future to enable effective planning of services."* (cited in Mencap/Lambeth, 2010; 8).

At the outset of the funding, the Carousel Project Manager began developing an accurate, up-to-date local database of adults (aged 18 and over) from Lambeth, on whom to base the project development plans. This register was to include people living in Lambeth with their families or in other settings and those from Lambeth who were in placements outside of the borough. To inform the project database, the local council offered some information from their own database which identified people with PMLD from Lambeth, generated using a screening tool with a specified criteria of PMLD used by the borough of Newham. [This was based on the accepted definition of profound and multiple learning disabilities from the PMLD network (nd) and the screening tool was developed with assistance from Mencap's national PMLD team at that time]. However there were some issues and discrepancies noted in the Lambeth data, with both the figures recorded and with accuracy in the identification of some individuals.

At the start of the project, Lambeth Council reported at a PMLD Sub-group meeting in July 2013

- 76 people with PMLD from Lambeth; 47 living *in*-borough, [30 living with families] and 29 living *out of* borough.

However, the project steering group suggested some inaccuracies and challenges to this original data:

- A discrepancy with numbers identified earlier
  - Lambeth PMLD Project Report [Mencap 2010]: 81 people
  - Current council database: 76 people
- A possible under-recognition of population with PMLD due to certain omissions. For example,
  - other individuals known to Lambeth Mencap not listed
  - those receiving out of borough/out-county services or placements
  - those recently returning to borough, following out of borough/out-county services or placements
- It appeared the agreed screening tool was not used consistently or with accuracy (eg some known individuals included do not have PMLD)

[adapted from Interim Report 2014: 3]

From the initial information shared by the council, when more accurately applying the agreed criteria defining PMLD, the project identified 34 individuals with PMLD *known to be living in Lambeth at that time*. Information gathered from a baseline survey of these individuals confirmed that their personal profiles did indeed meet the criteria of the PMLD screening tool. These people formed the origins of the Carousel Project database.

This data maintained differences from the local authority register (Project Milestones and Work Plan, March 2014). The 2014 data from Lambeth Council (February 2014) identified a new total of 62 people from Lambeth with PMLD - 36 residents with PMLD [25 living with families; 8 in residential care; 2 supported living; 1 shared lives settings]. They also identified 26 people placed out of borough

Over the duration of the project, the project database has very gradually continued to grow from its original 34 people as more individuals have become known and added to the record (each identified by strictly applying the PMLD screening criteria). Recognition and inclusion to numbers on the database benefitted from two-way collaboration and referrals between the Carousel Project, GSTT colleagues and other local services. The 2010 Lambeth PMLD Project together with the Carousel Project had alerted services to people with PMLD from Lambeth who were living in residential care homes, previously not always known to local services [for example as they were not eligible to day centre opportunities].

As of September 2015 a total of 68 people have been recorded on the project database from the outset, although not all are currently using the project services. Two individuals have sadly died during this time. Of the 68 people recorded, 8 are from other local boroughs. However, ongoing discussions with GSTT colleagues suggest that a notional 45 people identified with PMLD would be a closer and more realistic figure within the local population of Lambeth; this

figure would also equate with similar data from the neighbouring boroughs. This proposed number would suggest the Carousel Project is now successful in being aware of and/or providing opportunities for all or most of the Lambeth population.

Future recommendation:

A logical, next step would be to identify future needs for this changing population as early as possible, in order to plan an appropriate response. One clear suggestion would be to acknowledge individuals already known to other services and providers. For example numbers of those who will return to Lambeth from current out of borough placements [eg specialist FE colleges] and numbers of school leavers with PMLD who will be moving into Adult Services post school at 18 or 19 and may remain in borough. It is mandatory for education settings to begin transition planning from a student's 14+yrs annual review and schools from that point are required to share school leaver information with Adult Services and invite representatives to these annual review and transition planning meetings. The local council could maximise their strategic planning with these five years warning of young people with PMLD requiring their services.

### **5.2.ii Recruitment, attendance and retention**

The impact of continuing low expectations directly restricted project numbers increasing. Certain professionals (respondents identified social workers and care managers) perpetuated low expectations for people with PMLD from Lambeth: their views of the possibilities for these individuals rarely extended beyond meeting basic needs. This lack of awareness and limited experience resulted in very poor (if any) referrals to the Carousel Project. Their inability to 'raise their sights' for this group, undervalued and ignored the potential offered by involvement in the project. Local health professionals thankfully had greater knowledge and experience of people with PMLD; they recognised the valuable possibilities of Carousel Project activities and continue to promote the project and make direct referrals themselves.

Numbers taking up project activities have gradually increased after a very slow start, despite huge efforts to advertise and encourage greater take up. More recently stronger numbers have been established and appear to be retained as people develop confidence in the project activities. The project has responded to evolving demand and the popularity of certain activities by offering additional sessions to accommodate. Some of those joining the Carousel activities have emerged when GSTT services colleagues have alerted families, including some from neighbouring boroughs, about the appropriateness of the activities for people with PMLD, offered by the project. Attendance and take up from those living outside of Lambeth demonstrates how families and care providers value the Carousel activities – one woman who moved to Croydon regularly travels that distance to continue her Carousel sessions!

The slow uptake and *perceived* low numbers of services is not uncommon and is recognised elsewhere within the learning disabilities field. Ongoing research by The Learning Disabilities Observatory for Public Health England [e.g. PHE, 2013] confirms the Lambeth context to reflect the national picture. They note that 'estimates suggest that only 20% of adults with learning disabilities in England

are users of specialised social care services for people with learning disabilities' (PHE, 2013: 15). It would appear from local and national perspectives that the Carousel Project is responding effectively to those now known to both the project itself and to local authority services.

In a recent audit of Carousel Project activities, 51 attendances were recorded across the programme during one week [September 2015]. This figure includes some individuals who attended more than one activity. General trends of attendance are very good and the detailed project data enables staff to track in most cases every individual, week on week and activity by activity. Where it is indicated/ known, a small number of individuals show to have extended absences due for example to episodes of poor health or unstable epilepsy. Numerous absences however were recorded as issues about staff cover and transport rather than relating to the person with PMLD. This was a significant indication of some wider issues of overall involvement and participation in Carousel activities.

In future advertising and marketing of the Carousel programme of activities within the neighbouring boroughs and to the service providers based there, has the potential to further strengthen the reach of the project.

### **5.2.iii Developing a programme of appropriate and meaningful activities and access to the local community**

At the time the Lambeth PMLD Project (Mencap 2010) reported its findings, too few people with PMLD had opportunities for meaningful activities each day. Despite the personalisation agenda, there appeared to be a lack of progress for those with PMLD which meant there was little, if any, choice about how to spend their time and the project found there were 'not always high-quality options in terms of activity and support'. In response for those from Lambeth, a principle aim of the Carousel Project was to develop high quality, meaningful activities, as defined in this 2010 report

*What are 'meaningful activities'?*

- *They are stimulating and meaningful to the individual.*
- *People's physical and health needs are supported in a dignified manner.*
- *The person can access the community by taking part in activities that they find genuinely enjoyable.*
- *They recognise that many people with PMLD experience the world largely on sensory level and take this into account.*
- *People are included in community activities in ways that are meaningful to each person.*
- *Manual handling policy and practices don't act as a barrier to the person taking part in community activities.*
- *They recognise the importance of one-to-one interaction, with a workforce who are skilled in meeting complex health needs, and trained in non-formal communication techniques.*
- *Suitable and flexible transport is provided that enables people to physically move around their community.*

(Mencap, 2010: 40).

As part of the evaluation data collection, participants were asked to share the range and types of activities the people with PMLD undertook outside of the Carousel activities, including suggestions of how these people would spend their time meaningfully if the current Carousel activities were not available.

Few respondents were able to offer examples of activities or events that were commonly agreed to be 'appropriate'. Comments most frequently related to accessing the locality - such as 'wheelchair walks' along the South Bank or local parks in good weather or shopping malls and cafes in inclement weather. A few individuals shared some quite specific discrete or specialist opportunities the person with PMLD accessed - e.g. individual music therapy or aromatherapy. These activities were reported to be very costly or involved travelling some distance, but some also raised as a concern, that the opportunities they identified were all solitary experiences.

Responses were undivided and unanimous about how people would struggle to find meaningful ways to spend their time. Carers and support staff highlighted difficulties of lone working which often restricted what they could do [sometimes from a sheer logistics point of view to physically manage the person with PMLD outside of the home]. Crucially every respondent also offered great caution of the high risk that these individuals would very quickly become completely socially isolated and disconnected from any sense of community.

#### **5.2.iv Carousel activities**

The programme of activities offered by the Carousel Project continues, even after its two year lifespan to date, to be under constant development and review. It has now established some very successful 'core activities', in addition to other, shorter term blocks of activities and one off events.

When building the programme, identifying potential activities that were meaningful was a fairly straightforward process, taking suggestions from the 2010 report and responding to the more up to date ideas from family carers, from the Carousel Project's baseline survey (Interim Report 2014). A number of activities have now been very successfully established to form the basis of the 'core' programme which operates on four days each week.

The core activities include;

- Saturday Stories,
- Dance and Movement,
- Rebound Therapy
- Swimming

A measure of the project's success can be recognised by having to set up duplicate activity sessions to offer additional access to participants. Saturday Stories originally ran fortnightly, but is now offered every week as an option; Dance and Movement now runs two sessions on the same day [morning and afternoon] to respond to growing demand. There is a growing waiting list to join the weekly swimming session. One family carer exemplified the impact of the Carousel Project activities to offer a meaningful structure to the week through a

variety of opportunities for learning, engagement and physical activity for their relative.

#### **Case Study 4: Family carer describes some benefits of the Carousel Project**

***Our daughter is fortunate enough to attend the Carousel activities ... on four days each week.***

***Honestly, I do not know what we should do if Carousel were no longer in operation. Where else are we to find/create each year almost 200 regular suitable (accessible and 'appropriate' sensory) activities in suitable (accessible) premises, with suitable (accessible) changing facilities, to which her PAs/carers can take her?***

***The most important consideration is that these Carousel activities offer therapeutic and developmental opportunities to (our daughter) that make sense to her and, more importantly, she enjoys them (rather than fighting participation). They also provide social contact and friendship with a local peer group with which, should she no longer be able to attend Carousel, (she) would lose touch completely.***

Other activities have been added to the programme at different times, offered mostly as short blocks of sessions. These have included interactive sessions with a musical focus, massage and floor-based bodywork with the involvement from an osteopath and a series of creative workshops led by the English National Ballet based around *The Nutcracker*, culminating in a Carousel group theatre trip to watch a rehearsal of *The Nutcracker* performance.

However, the realities and practicalities of initiating these activities have not been an easy process – at times they have been impossible. The original proposal for this setting up phase of the project is now unexpectedly seen to be extremely overambitious, with predicted timescales now recognised as a very major underestimation. Establishing almost every activity session on the Carousel programme has taken inordinate amounts of manpower, time and great determination from the Carousel team and wider stakeholders.

#### **5.2.v Amenities in the local community**

Issues of suitability and accessibility have created a huge challenge for each activity idea separately. Genuine accessibility when relating to the numerous and complex needs of people with PMLD can challenge physical environments, including those that *are* considered to be accessible. Real and appropriate access for individuals from this minority group demands greater consideration and more especially when people with PMLD need to spend any length of time in an environment.

***The venue is crucial and we found it really difficult to find many places in Lambeth that are fully accessible.***

Carousel project manager

To clarify the needs of the Carousel context further, not only does a venue have to 'enable' the activity itself to take place in that environment [for example, the need for a swimming pool or trampoline or a venue large enough to accommodate a group of adults *with PMLD who are wheelchair users*] but it also needs to be *fully accessible to people with PMLD*.

In addition to the usual requirements for physical access to buildings access must respond to all potentially disabling issues and needs experienced by these individuals. For example this may include;

- specialist equipment – hoists, positioning for postural care or supportive seating
- space for *people with PMLD* out of their (large) wheelchairs *plus* their carers
- hygiene suites to administer PEG feeds, suction or other medical interventions
- Changing Places toilet

Mansell's (2010) report identifies clear recommendations relating to accessibility as a means to respond to responsibilities for 'place-shaping'. However, numerous obstacles and challenges the project encountered in the current local situation, often required some straightforward *reasonable adjustments* to access.

Challenges and triumphs in setting up the core programme activities.

The following table offers some examples of access needs and the reasonable adjustments required:

Activity	Needs, reasonable adjustments and access issues	Opportunities and outcomes
Swimming:	<ul style="list-style-type: none"> <li>• local pool</li> <li>• appropriately heated pool and changing area</li> <li>• fully accessible changing facilities [hoisting, adjustable changing trolleys],</li> <li>• full / differentiated access to the water</li> <li>• Changing Places toilet</li> <li>• weekly access, during daytime hours.</li> </ul>	<p>1. A new and very local leisure centre had a Changing Places facility, but the pool and ambient temperature [poolside and changing rooms] too cold to be accessible to those with PMLD.</p> <p>2. Eventual outcome:</p> <ul style="list-style-type: none"> <li>• sole use of hydro pool at Michael Tippett School</li> <li>• after school hours [4-6pm].</li> </ul> <p>Added bonuses –</p> <ul style="list-style-type: none"> <li>• venue was familiar to some</li> <li>• use of sensory room too!</li> </ul>

Activity	Needs, reasonable adjustments and access issues	Opportunities and outcomes
Rebound Therapy:	<ul style="list-style-type: none"> <li>• local leisure facility</li> <li>• sole use of a trampoline [ideally two].</li> <li>• full access to the trampoline via portable hoist [transfer between wheelchair/trampoline]</li> <li>• safe access to trampoline for those who are ambulant [steps with handrail-wide enough for 2 people together]</li> <li>• access to building</li> <li>• Changing Places toilet</li> </ul>	<p>1. A local leisure centre had trampolines but required a hoist for access. Despite many unsuccessful months of negotiating by the Carousel team for funding to buy this equipment an alternative venue had to be found.</p> <p>2. Eventual outcome: GSTT ran weekly Rebound Therapy sessions in a neighbouring borough, with appropriate access to trampoline. The Carousel Project negotiated weekly hire on a different day of the week.</p> <p>This venue however did not have Changing Places facilities, meaning some people could not stay longer.</p>
Dance and Movement:	<ul style="list-style-type: none"> <li>• safe floor for people to lie/crawl on the floor and move</li> <li>• adjustable heating control</li> <li>• adequate space for people with PMLD (in and out of wheelchairs) plus carers and other supporters.</li> <li>• Changing Places toilet</li> </ul>	<p>The venue used [MAC] was already used by Lambeth Mencap for other groups. It enabled sole use for this activity and had amenities for refreshments</p> <p>During the project use, with full support of those who manage the venue a Changing Places toilet was installed.</p>
Saturday Stories:	<ul style="list-style-type: none"> <li>• equipment for postural care</li> <li>• space to come out of wheelchairs and stretch</li> <li>• safe floor for crawling</li> <li>• Changing Places toilet</li> </ul>	<p>Local Day Centre agreed sole use of building on Saturdays.</p> <p>Added bonuses –</p> <ul style="list-style-type: none"> <li>• familiar venue for some Carousel attendees;</li> <li>• additional breakout rooms</li> <li>• kitchen facilities to make and heat food,</li> </ul>

**Table 3: Access needs, reasonable adjustments and outcomes**

Overcoming issues of accessibility such as those illustrated here were repeated for many activities in the Carousel programme. The eventual achievements were immense but necessitated some activities being located outside of Lambeth and demanding many weeks, months (and even years!) of focused attention from the project managers. Where activities were easier to set up, they took place in venues where the Carousel team had established working relationships with other services.

Suitability and location of venue was of great importance to carers as illustrated in the comment from a parent in Case study 5.

#### **Case Study 5: Parent describes some of the reasonable adjustments required by her daughter.**

***Those who have met my daughter ... personally, know how much energy she has that requires channelling into safe secure non-harmful pastimes if she is to remain happy, healthy, responsive, cooperative and working towards fulfilling her potential.***

***There are few appropriate alternatives for her, especially those which can be facilitated by just one PA and take place in venues with suitable changing places***

***.... (and where the opportunity enables her to be) independently mobile in appropriate safe floor-based environments (although non-ambulant)***

#### Transport

Finding affordable and fully accessible transport was a major issue for attendees of Carousel activities. Adverse weather, inappropriate access or inability to use public transport was a real obstacle to involvement in the project for some people. Collaboration with the local Day Centre by Carousel has resulted in short-term use of their accessible minibus with very minimal costs for those using it. However this 'loan' may be time-limited which will have clear implications for the participation and attendance of some people with PMLD in future

Access continues to be a challenging issue to address when planning for long term sustainability of the Carousel Project's core activities. Saturday Stories proved reasonably easy to set up by drawing on good partnership working with council run services; however the specialist resource needs of subsequent activities presented considerably more challenge. Some activities have been forced to use venues outside of Lambeth when local amenities were unable to respond to the evident issues of access to their facilities.

Travel is a clear issue – in addition to the costs of travelling beyond Lambeth, time is also a critical issue that severely impacts on the shift patterns of the paid workers. Most activities run across a two hour session with transport/travel time

at either end of the session. These activity sessions cannot be extended due to clashes with the usual shift timings. This restriction also limits opportunities for valuable social time that could occur ideally before and after activity sessions. If activities were sited in local venues, travel time [and costs] would be reduced and opportunities increased.

#### Wider benefits of local provision

A clear advantage of using local community facilities would be to raise the profile of this group of individuals with PMLD from Lambeth and more fully include them in local services. Frequent and regular activity visits would mean that over time people with PMLD became familiar with the surroundings and others using these facilities would develop a greater awareness of this part of their local community. Hopefully familiarity and confidence in using these local facilities outside of the Carousel activities would lead to further opportunities with the potential to enable valuable social connections and friendships in their own community.

## 6. Project approaches

The Carousel Project from the outset has engendered an ethos of person-centred thinking and working and in every aspect of its practice it ensures the people with PMLD are firmly at its heart. These values and approaches are now seen to be comprehensively embedded.

### 6.1 The pivotal role of the Carousel Project manager.

The Carousel Project managers have had a central role for people with PMLD within and beyond Lambeth. Their vital actions of presenting themselves as advocates and 'PMLD Champions' to commissioners and other local professionals continues to be a pivotal role to improved services and quality of life outcomes for this group. Their high expectations and aspirations for this population are fully backed by their expertise and knowledge in and about effectively meeting the lifelong needs of this group. They continue to very positively raise the profile of people with PMLD to other professionals and community providers [in Lambeth and beyond], providing excellent and necessary role models for the many services and facilities involved in improving the lives of this group.

The original manager was catalyst to this landmark change in Lambeth. As a direct response to the 2010 Lambeth Report, she worked with family carers to instigate this project and to set wheels in motion to initiate the Lambeth PMLD Sub-group. This Sub-group facilitated a shared focus on this population by bringing together the local commissioner, service providers and wider stakeholders to raise the profile of people with PMLD in Lambeth and by raising the expectations of service commissioners and providers, to address their unmet needs locally.

The project managers are particularly skilled not only in their professional expertise with the population of individuals with PMLD, but as crucially in working very constructively with all the other stakeholders involved. The impact of their motivating and enabling approach reaches beyond those individuals with PMLD themselves, to their families, their paid workers and others from the local communities who provide amenities, health and social care services.

A central and very significant factor in the overwhelming success of the Carousel Project has been the expertise and experience of the project manager in this very specialist field of profound and multiple learning disabilities.

The project managers to date have crucially brought with them a vast range of essential and specialist knowledge, understanding and skills in enabling and supporting individuals with PMLD. In terms of the activity programme and the full inclusion of its many attendees, the manager and later the core project team, have indispensably demonstrated immeasurable expertise in facilitating creative and interactive workshop activities to personalise and embrace the needs of people with PMLD and as importantly, to motivate, enable and support carers and paid workers in attendance. These combined were key skills to the success of activities for both beneficiaries.

The experience of one carer illustrates the wider benefits of involvement.

### Case Study 6 Reflections from a young carer

**A young carer** ~ supports his brother at the weekly swimming sessions

Early in the project, this young carer commented on some of the practical benefits *for himself as a carer* from attending the swimming sessions. By watching Carousel staff each week, he learnt how to use the hoist to transfer his brother from his wheelchair. Over time, working alongside experienced staff he had developed confidence and now used their hoist at home. When the hoist was broken, having a physio regularly attending this session meant this issue was fast-tracked to respond to the family's urgent need.

Carousel staff have been seen as role models and offered direct guidance which he saw very positively ~ ***'makes me feel important to help – to be more supportive in his life and understand him and what he needs'***

For him (as carer) some of the *'best things'* about his brother attending the swimming sessions were ~ ***'seeing improvements - he knows he's coming swimming – he laughs, gets nervous, loves it – he sleeps well after swimming - that's not usual for him – so our parents sleep well too!'***

For his brother he highlighted the importance of swimming in the hydro pool ~ ***'best thing – (his) muscles are getting tenser – more relaxing - and stretching is important for him. Can tell (he is) relaxed and stretched out in the pool, then massage and the cool down afterwards - he's relaxed already, it's better'***

In addition to the hydro pool activity, his brother regularly attends the Dance & Movement sessions and Saturday Stories, supported by other, paid carers. Physios and Carousel staff have all commented on the noticeably increased confidence they have observed in those in the carer role with this young man when following his postural care support plans – both the physio regimes and positioning advice. This is of particular importance to maintaining the integrity of the young man's body shape and appears now to be demonstrating evidence of these benefits.

After 10 months of attending a number of Carousel activities, this young carer reported that his brother now ~ ***'can straighten out much more since Carousel'***.

This family carer described some of the added and unexpected benefits arising from his involvement in the weekly Carousel hydrotherapy session – during family holidays ***'if we went to the pool...I know what to do now – and I'm confident too!'***

## 6.2 Supporting people with PMLD

### Carousel expertise

The project values and principles are strengthened by the profile and skills of the project team – again presenting a model of good practice to other services. Their team offers a skills set essential to meeting the complex needs of this population. For example they are experienced in manual handling in addition to, at very least, basic competencies in physical management; in using intensive interaction, a specialist approach to promote and enable communication; in specific interventions such as rebound therapy. The project continues to invest in its workforce with training and development opportunities necessary to address the holistic and complex nature of effectively supporting people with PMLD.

### Carousel approaches

Some of the Carousel approaches and their benefits that have been observed to directly influence outcomes for people with PMLD identified through the evaluation process include:

- Person-centred approach; affords flexibility to be as responsive as possible to individual preferences and interests, differences and needs - at any moment in time, progress has been demonstrated on many occasions.
- Holistic approach takes account [for every individual] of their physical comfort and wellbeing, access issues and the required pace of each person to take part.
- Regular monitoring and review of individual and group responses to each session – informs planning for the group and individuals within it. Staff plan effectively for individual differences through differentiation for example by role, action, resources and often motivational or favourite elements such as musical preferences. Improved levels of engagement are as a direct result of their approaches.
- All activities reinforce and build on the information, guidance and advice from others involved who know the person with PMLD very well – family and professionals e.g. physio, speech therapist and intensive interaction experts.
- Quality of relationships are key and the development of all interaction and social connections are viewed as vital and enabling to the person with PMLD.

The observation of Delores initiating interaction was a new response – and one she clearly enjoyed.

### **Case Study 7 Developing social interaction**

#### **Delores – it's more fun together**

Delores was ready to take part in Saturday Stories. She sat in the circle with her usual support worker on one side; on the other side was a male support worker whom she didn't know and who didn't know her. I was told that because of her significant dual sensory impairment, Delores often gets anxious. It was explained that she really lacks confidence in many aspects of her life but in particular her mobility and interaction with other people and as a consequence, she prefers to sit fairly passively during all of the session activities.

To accommodate a late arrival to the story session, the circle of chairs had to move closer together. By accident Delores's arm had nudged the arm of the man sitting to her side [someone else's support worker]. He turned and leant towards her; he spoke to her as he pushed his arm back against hers in fun – she moved her arm immediately - to nudge the man again. He noticed what was happening and responded by nudging her back then waited with his arm very close to hers... Delores repeated the nudge and turned her head towards him. He laughed and spoke to her returning the nudge. This interactive sequence continued for a few moments with this usually passive individual clearly 'in charge' and enjoying this turn-taking game!

During the session, that day's sensory story was about a celebration - a party and there were some repeated opportunities to 'dance'. The man sitting next to Delores took her hands and motioned to her to 'ask' if she wanted to dance with him. She stood up while holding his hands and 'danced' with him slowly for most of the song. Delores appeared to be aware of the situation with someone new, but didn't look anxious. When she sat down again she remained relaxed and calm.

Several observers commented on her achievement – interacting with an unknown person but also taking part in the dancing so confidently too.

### **6.3 Wider project approaches – collaboration and partnerships**

The Carousel team built on many existing networks and partnerships to further the progress of the project developments. 'Hubbub', one of its early developments was involvement in a collaborative endeavour with the Lambeth speech and language therapy team and *Us in a Bus* [a voluntary organisation] to set up and run a series of training sessions for the local workforce, followed by

blocks of guided activity working directly with the people with PMLD whom they routinely support. These weekly 'Hubbub' sessions used *Intensive Interaction* as a recognised approach to enable people [with PMLD] to connect with others through interaction, play and self-expression. The collaboration extended further to benefit the Carousel attendees directly as the sessions themselves were jointly facilitated. All supporters and carers were supported by the 'joint team' [Carousel, Us in a Bus and speech and language therapy colleagues], to use their newly learnt skills directly with the person whom they support. As a direct consequence, the speech and language therapy team got to see a larger number of their caseload in one place; Us in a Bus 'experts' helped engender skills and confidence in the workforce and Carousel staff got to know both the people with PMLD who were new to the project and their carers.

As an added benefit of collaborative working, the local Day Centre manager's willingness enabled the Hubbub activity to take place in the centre building. This facility was fully accessible to people with PMLD and in fact, the venue was already familiar to some of them. This working relationship had led directly to other Carousel activities taking place at the centre. Saturday Stories has sole use of the centre building for its long session on Saturday's affording people the space and time for socialising over lunchtime. Offering the kitchen facilities enabled people to heat pureed food or prepare other appropriate refreshments.

Good partnership working has been established between GSTT physiotherapy and speech and language therapy teams, through their advice, training and support for Carousel staff, their regular attendance and joint working and involvement in some core Carousel activities and by the activities themselves complementing the key blocks of interventions carried out by these healthcare teams [such as Rebound Therapy for example].

This ongoing collaboration enhances the benefits and outcomes for all concerned; people with PMLD get greater and more regular access to the expertise of GSTT professionals and other stakeholders gain easy access to their advice and support; the Carousel Project benefits from person-centred programmes and more rigorous monitoring for every individual in addition to more generic advice, for example on access, positioning and postural care. This approach to joint-working adds to the reputation of the project, making it more appealing and reassuring to new participants.

This reciprocal partnership working facilitated by the Carousel Project already leads the way, particularly when considered together with the Lambeth PMLD Sub-group which draws together wider stakeholders to explore needs and provision locally. The collaborative developments and effective lobbying by this group was significant; they positively influenced many local changes which directly impacted on provision for people with PMLD. For example raising the lack of therapy input for this population [compared to neighbouring boroughs] led to the appointment of an additional specialist physiotherapist in Lambeth; significant funding was generated by the work of this group to set up a pilot phase for the Carousel Project. The inclusive approaches adopted by the project and this Sub-group offer great potential; many of the principles of the Co-production agenda (SCIE, 2015) are already established.

GSTT health colleagues actively promoted the Carousel Project as they recognised and valued the comprehensive benefits of the activities, clearly illustrated in the following testimonial:

### **Case Study 8: Health Professional endorsement to the benefits of the Carousel Project**

***The Carousel Project serves a specific local population with life-long care needs that require sustained services. The services provided by the Carousel Project will allow therapists to hand over some aspects of ongoing management to support staff to manage and monitor in-between blocks of health input with collaborative working that enables early identification of concerns and appropriate response. This helps improve service delivery and health outcomes for the individuals***

***The activities in themselves also have carry over health benefits for the people who attend. It appears there is an increasing population of people with learning disabilities and complex needs living with aging or elderly parents who find it increasingly difficult to provide physical support. Attendees especially benefit from the movement group and the water-based sessions where the person is able to receive input for physical maintenance programs that it would not be reasonable to expect aging family carers to do. The maintenance of mobility, posture, range of movement, and respiratory status are just some of the benefits of these sessions which have a significant impact on peoples' health needs.***

***The introduction of the trampolining/rebound sessions by Carousel Project also offers a meaningful physical activity in a format that can provide physical health benefits for people who would not access other sessions within a public leisure centre. Alongside this the trampolining/rebound sessions can also be used to address sensory, engagement, and communication needs.***

***The provision of this service is an important step towards addressing physical activity for healthy lifestyles within this population to promote equity and reasonable adjustment in physical activity provision.***

## 7. Sharing information, listening to and supporting carers

Despite increasing recognition of the key role of family carers to the lives of those with additional needs, and more especially to the significance of this to people with PMLD their expertise continues to be overlooked, undervalued and underused (eg Mansell, 2010; Chadwick *et al*, 2015, Goldbart, 2015).

Valuing and viewing 'carers as experts' was a central premise of the Carousel Project; this tenet created the underpinning for the project's work and was advocated and promoted at every opportunity. Speaking of this, the Carousel Project manager reflected, *'the project would have failed at the first hurdle without this emphasis'*.

The successful and true involvement of families and others can be a challenge, however great their need and however supportive the provision or services may be; families are often described using language such as 'hard to reach'. SCIE (2008; 1) recognise the importance of overcoming this challenge; *'Ensuring that the voices of seldom heard service users are not marginalised is a key challenge for practitioners and managers. It is crucial that people from seldom-heard groups are able to take up the opportunities presented by the personalisation of social care services'*. They offer an alternative perspective to that which places emphasis on the individual as being responsible for the lack of involvement. They suggest 'seldom heard' valuably alters that position, offering a more constructive view and shifting the 'responsibility' on to agencies rather than those on the receiving end of services.

When considering the best ways to enable families and others to be included and to participate, particularly for those with a relative with PMLD, we must consider the full context. It is a gross understatement to suggest the impact of the lifelong role of being a family carer is immense. For this particular population, when the support for their relative's needs is so great, most aspects of the carers' lives are affected by constant caring for their family member 24/7.

Turner and Giraud-Saunders (2014) consider many themes common to this project in the issues and challenges they identified in supporting people to successfully use personal health budgets. They describe 'Family carers ... are often spending so much time and energy on care-giving that they have no capacity to participate in meetings'. They acknowledge additional barriers, 'People with learning disabilities and their families are not always in touch with local support groups, and local learning disability groups are not always well connected with mainstream public involvement networks'. Their guidance advocates creative approaches in attempts to meaningfully include and involve families and others – 'Involving people with a range of needs, including ....family carers who are tired, requires a variety of methods. This may include, for example, email, text, social network media and individual contacts in addition to conventional meetings. (Turner and Giraud-Saunders;2014: 12)

Chadwick *et al* (2015) shared insights from family carers on their experiences in accessing health services for their relative with PMLD. They offer some additional perspectives to consider with regards to this project review. This research affirmed the huge additional caring demands on this distinct group of carers but also learned about the stigma sometimes encountered, which carers claimed negatively affected their own wellbeing. The parents in their study described how hard it was to trust others with the care and welfare of their family member, and in particular how disempowered they felt when their expert understanding of the very unique needs of their sons or daughters with PMLD were often overlooked or ignored.

The stakeholders of this evaluation also reported that low expectations were an influence on carer involvement. They described the impact of these low expectations held both by some professional groups [views specified local authority Care Managers and Social Workers] and by some families and carers. These expectations related to the potential of individuals with PMLD but also to their expectations not encompassing aspirations or outcomes beyond meeting basic care or respite needs. Some families were discovered to have been given no awareness to expect even the most basic entitlement to support and as a consequence saw no point in getting involved.

There is much evidence of the Carousel Project team striving to reach Lambeth families and carers of people with PMLD, currently with minimal returns [eg evidence from Quarterly Project Reports, Project Milestones and Work Plans and discussions with those in the Project Manager role]. The project team continuously promote and advertise the Carousel Project and its activity programme. They respect carers as 'experts by experience' and in trying to hear the voices of the 'seldom heard', have even visited service users and carers at home to see how activities could be tailored *even more* to meet the needs and interests of their family member.

A variety of approaches have been regularly employed to reach families and carers with the aim of improving levels of engagement and participation in the Carousel Project, for example;

- programmes and project information -regularly posted on the Lambeth Mencap website,
- flyers posted to those on the project database
- flyers shared with health colleagues, Adult Learning Disabilities Services, Day Centres, residential homes and other stakeholders
- Activity Open Days
- planned training opportunities – some of which had to be cancelled due to poor response.

For similar reasons, plans for Carer Focus Groups as part of the Evaluation process were also cancelled from the review cycle by the project team.

The project team report that the support and interest they currently receive about the project is from a discrete few family carers. These carers held high aspirations and expectations for their sons and daughters; they also tended to be those actively involved in the local consultative PMLD Sub-group. However, as the positive profile of the Carousel Project is raised its concentrated focus on developing the activities programme, may shift to now explore greater

involvement with family and paid carers. As the project profile is gaining wider acclaim, especially through word of mouth by those already involved, so the necessary trust from carers may evolve. A future step may now be to explore the ideas advocated by SCIE (2008), *'how through an integrated way of working the participation of people from seldom-heard groups can be enabled'*.

The obvious practicality of insufficient respite may be the major obstacle to greater involvement of family carers – not being able to attend or get involved in opportunities because they are busy caring for their relative. Despite identifying a clear shortfall in respite and short breaks for Lambeth carers (Mencap, 2010), this situation remains largely unchanged several years on. Family carers told this project that despite having their needs as carers formally assessed, they continued to experience a lack of respite from their caring role [Interim Report, 2014]. Only one quarter of those participating expressed they received respite to enable them to have a quality of life themselves. The interviews discovered that one 85 year old [disabled himself] sole carer of someone with PMLD had no weekend support to aid him with the practical side of caring for his relative. As a consequence, both parties were severely compromised in every aspect of safety, personal and health care, dignity and opportunity (Interim Report, 2014; 20).

In order to develop stronger partnerships with families and others carers from Lambeth, creative approaches are needed to address the inadequacies of respite provision, which demands the involvement of local social care services. If adequate respite opportunities existed, then there could be real possibilities in Lambeth, for co-production to begin.

The following vignette details some insight into the lifelong caring role for families, highlighting the potential impact on wellbeing for the carer themselves and the clear need for respite to counteract this heavy demand.

### **Case Study 9: A mother reflects on her daughter's progress and the impact on her own life.**

#### **No respite - little time to leave the house, let alone for a life of her own?**

Lydia, now nearing the age of 40, had a long history of special schools and adult services that were not able to adequately meet her complex and challenging needs. In the past, attendance at the local day centre was problematic and required her Mother giving up hours and hours on each of the 3 days she attended, to physically escort Lydia to the centre on foot (Lydia couldn't cope on transport). Once there her Mother physically supported her distressed daughter to make the transition over the threshold into the building -only to be called back 2-3 hours later to collect her and repeat the struggle in reverse.

During this transition into the centre on each visit, Lydia's anxieties would be so heightened the situation always resulted in self injurious and distressed behaviour. Due to such levels of distress and anxiety, Lydia had no positive experiences of trying out activities that were accessible, enjoyable or meaningful to her.

So this Mother's previous recollections of daytime provision for Lydia involved too many highly stressful hours getting her into the centre, which probably required as much time to recover from emotionally ~ not exactly any respite!

In the two years of involvement in the Carousel Project, life has turned a corner for both Lydia and her Mother. Over time, as things became more familiar and predictable to Lydia she became more relaxed and despite her sight impairment she became increasingly secure and trusting of the situation. This progress allowed her to have the confidence to become progressively more involved in the activities each session. In turn this confidence enabled Lydia to sometimes sit near or with others from the group at lunchtimes and develop some sense of being part of the regular Saturday Stories community.

This activity over that period of two years has now become central to her daughter's regular whole day on Saturdays; walking to the session from home with her support worker, taking part in the activity at her own pace and eating lunch often alongside her peers. She now shows not only clear signs of enjoyment and but also of wanting to be included.

Incredibly after so many years with little respite, her Mother now has this one day to herself each week. As an extra bonus, the Mother reports when Lydia comes home on Saturdays ***'she is always tired but happy. Saturday night is an early night for her and she usually sleeps well'*** (not always the case!) ***(Lydia) has a history of disturbed nights ..... but she certainly sleeps soundly on a Saturday!***

To add to that, this Mother importantly reports:

***The impact of this on my own health and wellbeing is small but significant. Because I have the cover and (Lydia) has somewhere specific to attend, I can relax. In fact, I love my Saturday afternoon matinees and have been to many plays over the past couple of years.***

## 8. The wider workforce, training and support

The quality of social care services is influenced by the knowledge, experience and consistency of support workers and carers (DRC/DoH, 2007). We know this to be of even more significance for people with PMLD where their distinct and complex profile of needs creates extra demands of skill and expertise by everyone involved in the care and support role (eg Mansell, 2010, Mencap, 2010). Lambeth carers in the 2010 report emphasised this need to develop a workforce of *'highly skilled staff who can engage with and care for their child as they would themselves'*. However the picture reported in 2010 by Mansell and locally, in Lambeth, highlighted shortfalls within the skills and expertise of those supporting people with PMLD. Despite clear and focused recommendations from both reviews, these issues continue to be a concern in need of attention, as surmised from this evaluation feedback.

The Lambeth report clarified the knowledge, understanding and skills necessary to meet the needs of individuals with PMLD and the magnitude of that gap. *'Staff need to have the right skills so that they can meet the person's communication and often complex health needs. Lack of the right skills can have serious consequences in terms of the person's health and quality of life'* (Mencap, 2010:16)

There appears to be a similar picture elsewhere, which may be of value. For example, a review in New Zealand looked very specifically at the workforce supporting people with PMLD, whom they describe as having 'high and complex needs' (Te Pou, 2013). Similarly to the Lambeth recommendation, their objective was to build *'a competent workforce that highly values and actively supports disabled people and their families'* and in this particular study, those with high and complex needs [PMLD]. Their investigation first identified the support needs of the PMLD population and then the key skills and competencies required by the workforce to meet these needs. They ascertained *'a number of generic skills required by all workers supporting disabled people were identified, along with specialist skills required by workers supporting disabled people with "high and complex needs" specifically.'* Te Pou's recommendations offer insightful ideas for the UK. To build on core *generic skills* training they suggest the addition of essential training electives - *specialist skills* to meet the needs of people with PMLD. Their recommendations are based on New Zealand's nationally recognised, mandatory qualifications [funded by their Ministry of Health] for those in support and care roles for people with disabilities.

Stakeholders' views acknowledged some of the challenges of an inexperienced and untrained workforce, also illustrating 'inconsistency' as another distinct concern. This related to the considerable turnover of support workers. Examples were again detailed in the earlier Lambeth Report, *'There is often a high turnover of support staff, so just as someone gets to know the person well they leave and the whole process starts again'*. This situation is not unique to the PMLD field however, with staff turnover acknowledged to be high in disability services generally (van Dooren, 2015), albeit the direct impact on individuals with PMLD is likely to have even greater significance.

One considerable challenge for this evaluation process, was that a sizeable number of people sharing their views and observations (at various phases) were either new to the Carousel activities, completely new to working with the person with PMLD or even, new to the support role entirely. In such cases they were unable to interpret the communication and responses of that individual with any accuracy, neither were they confident or familiar with the best ways of supporting and enabling that person.

This noteworthy issue of consistency [of support workers] created an unexpected and ongoing challenge for Carousel staff. As a consequence of new or unfamiliar support workers attending, Carousel staff would often need to intervene directly and provide models of support and interaction. Without such intervention, some people with PMLD were not enabled to access the activities or gain most benefit from their involvement due to these new/unfamiliar support workers. Carousel staff undertook this support of the workforce whilst also leading and facilitating the activity for the wider group.

Involvement of the wider workforce has been a key facet of the project's progress. For people with PMLD to gain the greatest benefit from involvement in the activities, they need the full participation and engagement of their support staff. For some support workers, this change from their 'usual' support role presented a personal and/or professional challenge; for others an opportunity – or a combination of both!

During the evaluation process, many people shared their perceptions on these differing outlooks. Family carers for example, explained how difficult it was for their paid PA who was used to lone working in their family home supporting the person with PMLD in very everyday routines, to now be expected to join a group and take part in 'all sorts of creative activities' in front of people they didn't know.

There were a number of quite opposing views and reflections from people participating in the evaluation, highlighting the diversity of knowledge, skills and relevant experience held by the range of stakeholders commenting. All views collected offered useful and differing insights on the support worker's role, whilst support workers themselves shared their 'experiences' of how attending Carousel activities had presented challenges and welcomed opportunities. Many commented on issues of confidence. For a sample of illustrative views on these issues see Appendix 3.

This evaluation captured many valuable perspectives and insight on workforce training and development issues. These views were gained from individuals, through ongoing discussions and in-depth interviews with Carousel staff and other project partners.

The Carousel Project employed a range of valuable working practices that enhanced the knowledge, skills and understandings of the wider workforce – many collaboratively involving other professionals and extending the expertise available through the project activities. The programme of activities created ideal opportunities for reciprocal sharing of expertise and ideas. The overall ethos of the project and the skilled approaches of the practitioners facilitating the sessions were, a positive influence on those attending. They demonstrated

excellent models of practice, relevant and specialist approaches and creative ideas to promote engagement and active participation in the people with PMLD being supported. Many people commented on the professional learning and wider benefits for their paid role from attending the project activities – and as a result extending this to their own work setting or when supporting someone in their family home.

Some comments illustrating the perceived value;

Home manager: our staff ... *'learn a lot – take it back, try and incorporate it back at home ...like the exercises [we] tried at home'. 'WE get taught – get the support you need... shown what to do and how to do it. WE get the support'* [her emphasis].

Support worker: *'we love the sensory room and doing massage here – we do that at home now'*.

Home manager: *'we found out more about [person they support] through Carousel sessions – like lying on her front – chance to see a whole different side [ie aspect] to her'; 'learning from each other is definitely helpful, sharing our knowledge both ways. Danny and Joy share lots – then we share it with families and that's really important'*.

#### Training and support

The Carousel Project has collaborated directly with local experts and healthcare specialists to plan and deliver specific training and support opportunities

The project team has worked closely with the GSTT specialist learning disability physiotherapy team to address the lifelong postural care needs of people with PMLD participating in the Carousel project. Professionals from GSTT provided training to develop knowledge and basic skills to meet recognised basic competencies. Carousel staff, that were included in this training, now use and share these essential skills throughout the programme of project activities. For each person with PMLD attending the Dance & Movement sessions, the GSTT team developed easy read physio programmes using photo illustrations. These physios regularly take part in the sessions, on hand to coach and mentor support carers as well as monitoring individuals receiving the physical management.

Another partnership training example was the development of the Hubbub sessions, described earlier in this report. The 'kernel of an idea' for this originated from discussion between a Carousel Project manager and the Lead Integrated Services Commissioner for Lambeth; the outcome was a leading-edge model of training for support staff. It comprised blocks of training initially, followed by on-going mentoring and support via 'guided activity'. The premise of this innovative model was to first facilitate the training and up-skilling of Intensive Interaction 'champions' who would then become lead practitioners for their work-place colleagues. This inspiring model was based on a strong collaboration between Carousel, GSTT speech and *Us in a Bus*, a charity who are experts in Intensive Interaction. This initiative also enabled Carousel to train members of its own team for their wider role in supporting people with PMLD and in supporting those in carer roles.

However, recruitment on a longer term was not sustained. A key partner in this development offered reflection on likely causes of this limited take up. Involvement in this training required a commitment to attend at least the initial 8 weekly training sessions. To be successful, managers also needed to give their commitment to enable this to occur, as a minimum, to ensure support workers were on a rota to attend. The consequence of poor take up for this workforce training led to Carousel moving its limited resources to other developments. The Hubbub now operates on a more traditional model of support, led by the local speech and language team.

Nevertheless, those organisations and providers who *had* fully taken up this valuable training opportunity offered excellent feedback- for both the staff team and ultimately, the impact of the training on residents in their care.

Manager of two homes: *'Hubbub – is the project we started with and offered us an ability to improve our intensive interaction and story-telling skills as a staff team. We used this a lot at the start of the project and alongside the work we were doing in the house supported the teams' development in this area. We noticed a large change in 1 resident who had severe dual sensory impairment who became more engaged and confident as a result of starting this work'.*

These joint-working relationships set up by Carousel involving experts in the field of PMLD have clear beneficiaries. In addition to the individuals with PMLD [who gain the positive experience and outcomes from the intervention], support workers, family carers and the wider workforce including the 'the experts' themselves, continue to learn, build on their own professional skills and importantly reflect on practice as to *'what good looks like'* for this population.

The Carousel Project, through its activity programme and partnership-working has created innovative opportunities for the training and further professional development for healthcare staff. GSTT healthcare professionals from other boroughs have spent time visiting Carousel activities for example and a number of final year university trainee physios have completed successful practice block placements here.

Feedback from some trainee physiotherapists highlighted the value they perceived from their placement in this distinctive opportunity.

### **Case Study 10 Project impact on the wider workforce**

Opportunities for the future professional workforce - Student physiotherapists:

A number of university trainee healthcare professionals had chosen to get involved in supporting the Carousel Dance & Movement sessions for their final 8 week practice placement.

An informal discussion identified some clear benefits they felt this opportunity had offered them;

- a unique opportunity to have hands-on practice with people with PMLD – saw this as quite a rare situation
- they gained valuable experience of seeing individuals and their wellbeing as a 'whole person'
- a very different context for working - unusually it was a 'creative context' rather than a clinical setting.
- new insights that broadened their learning from the experienced Carousel Project staff – things like communication styles and approaches to engage people with PMLD.
- they valued the chance to work with, and alongside carers themselves.
- they felt the overall experience was very worthwhile- and equally they felt able to offer carers practical advice and reassurance.

This was unquestionably viewed as a very valuable opportunity - gaining skills and experience to take into professional practice on graduating the next month.

## **9. Concluding remarks and recommendations**

In developing appropriate and responsive provision, this Lambeth based project encountered, at first-hand, many of the barriers and social exclusions faced nationally by the population of people with PMLD and their families.

The Carousel Project and this evaluation reaffirmed that the essential needs of this group of individuals, requiring reasonable adjustments and full accessibility are rarely considered by communities and local services, in fact, more often are overlooked entirely. Equally of importance, their families and carers as a consequence also experience isolation, poorer quality of life and adversity on many fronts.

Despite perpetual legislation to prevent discrimination and to mandate equality and government driven strategies to address the accepted and persisting inequities in access to services experienced by people with learning disabilities, prejudice, barriers and inequalities remain. As a direct consequence people with PMLD in particular, continue to be on the social margins of their communities and at the foot of the agendas of local authorities and service providers. The very reason for the Carousel Project's existence!

### **9.1 Carousel Project outcomes – raising our sights**

Working within such long established limitations demanded great skill and determination from the project managers. To overcome values in need of such significant cultural change have without doubt hugely hampered the project and its progress towards fully meeting the proposed objectives. The presenting barriers and challenges created unavoidable and considerable impact on deliverables. Nevertheless, they slowed but did not prevent substantial and convincing outcomes to emerge from the Carousel Project developments.

The extremely positive and wide ranging achievements of this innovative project to date are clear from the evidence presented from this evaluation process. This report demonstrates that people with PMLD from Lambeth [and beyond], and the wider stakeholders, are already reaping benefits from this important initiative. As the Carousel Project's unique provision of relevant and high quality opportunities continues to develop and attendee numbers grow, its worthy reputation is also gaining well deserved attention. The cumulative effect of this development is creating even further interest and demand for involvement.

### **9.2 Raising the bar**

This project established very ambitious intentions from the outset of its journey and in particular, those objectives proposed to the GSTC funders (Lambeth Mencap, 2012; for detail see Appendix 1). The broad objectives stated;

By providing access to increased levels of physical exercise and activities, the objectives of the project and the changes we expect to see are:

- Improved access to sustainable services for people with PMLD
- Health improvements for people with PMLD
- Health Improvements for Family Carers of people with PMLD

The aspirational objectives were based on a clear vision, specialist expertise, strong commitment and drive from the original project manager [also the initiator of this project] and other, experienced, very involved and equally passionate stakeholders. These proposals set an exceptionally high bar to address the unmet needs experienced long-term by the people with PMLD and their families from Lambeth, to improve their health and lives and to enable them finally to be fully included within their local community.

These objectives and the detail of the supporting statements [see Appendix 1] by which to judge improvement and change were ambitious and challenging to meet, particularly given the historical lack of progress for this population [locally and nationally], but more especially within the limitations of the two year funding timescale. Judgements of perceived improvement also proved very challenging to ascertain for this specific population of people with PMLD, where more realistically indications of improvement or change demands review by longitudinal study.

In retrospect aspects of the plans may seem overambitious but they were certainly necessary in this London borough. The high expectations were well thought-out as a direct response to the lack of progress to develop local provision for people with PMLD (Mencap, 2010; Mansell, 2010). The bold intentions of the proposal also reflected the very positive experiences from the scoping phase of the project, where earlier developments proved very straightforward to achieve. Nonetheless, the accumulating evidence from this project establishes undeniable evidence of progress on many fronts – many of which contribute considerably to the far reaching objectives of this project, for individuals and in establishing local provision.

### **9.3 Local expectations**

The findings of this evaluation through stakeholders views, identified that some professionals from Lambeth continued to hold limiting views and low expectations of people with PMLD, as reported by Mansell (2010). Furthermore, this standpoint had a damaging influence on the expectations of some families and carers. More importantly, it had a direct and adverse impact on the opportunities and support offered to those with PMLD by the local authority. Respondents commented that even at annual reviews [which were reported to be very rare] there were commonly no discussions of the need or access to meaningful activities or in fact, anything beyond meeting basic care needs. Consequently there were no proactive referrals to the Carousel Project from care managers or social workers and this deficit was clearly reflected in funding packages for individuals.

Harflett *et al* (2015) identified this population to be at greater risk of isolation and denied their full entitlement to personalised services. In particular they noted that this group was also less likely to have the support of advocates to

voice this disparity. This was certainly the situation for people with PMLD from Lambeth, where there appeared to be no advocates or independent brokers researching opportunities for appropriate activities to improve lives and the wellbeing of these individuals. These individuals with PMLD would have benefitted from 'care service navigators' (eg Leicestershire NHS Trust, 2013) to ensure their needs were adequately and equally met.

## **9.4 Health improvements**

In recognising the countless variables impacting on health status and improvement, we cannot directly infer influences from project involvement. However by adopting this project's more holistic, whole-person view, we can substantiate small but incremental improvement and change to the general wellbeing and quality of life for individuals with PMLD who have been taking part in Carousel Project activities and where we have the data, some indications of improvements for family carers too. A longitudinal appraisal in future could offer important and valuable information about potentially improved health status of people with PMLD and their family carers.

## **9.5 Improved access to sustainable services**

This evaluation identified countless obstacles of accessibility and a chronic need for reasonable adjustments to be implemented within the local community, meaning that people with PMLD were unable to use their local amenities as their non-disabled [or even less disabled] peers. The project attempts to procure reasonable adjustments posed immense blocks in its developments across the duration of the funded phase, with little sign of change in the attitudes and willingness of some community venues to actively respond to issues of access and true inclusion.

Despite such incessant hurdles, the Carousel Project programme has persisted in developing relevant activities for people with PMLD locally. Their needs necessitate small group sizes in order to be of most benefit to these individuals. As a consequence, continued recruitment and demand from increasing interest for greater involvement, has resulted in repeat sessions of core activity being offered, and in the case of swimming - a growing waiting list!

The major issues of securing appropriately accessible venues played a major part in the project's slower than expected rate of progress and disappointingly required some activities to take place outside of Lambeth. In turn this delay impacted enormously on recruitment, with many attendees joining the activity programme in very recent months. Regrettably the timing of this evaluation therefore, is too early to generate the most worthwhile data. The greater involvement of people with PMLD *over time* will enable a clearer picture of improvement and change in health status and in the making headway towards the development of sustainable services in Lambeth, using more trustworthy evidence.

## 9.6 Measuring future success

A valuable future step would embed evaluative practices in all future project and partnership developments. Identifying clear objectives and outcomes, including quantifiable, shorter term increments would enable indications of progress and quality to be more easily recognised and measured. Developing a multi-level approach will enable the project to monitor and review outcomes for both individuals and the provision against internal measures and against both local and more independent, neutral external indicators.

For example, identify project outcomes with indicators of progress or quality

- For individuals with PMLD attending Carousel activities [developed in partnership with those who know the person well]
  - collect baseline information from attendees eg on health indicators, budget allocation etc [with consent]
  - identify meaningful and personalised targets/ outcomes [giving a clear focus on what to look for as an indication of progress and change]
  - develop simple, accessible session records that reflect this personalisation [records that give a clear focus on 'what to look for']
  - map this to their Person-Centred Plans and wider outcomes [internally and locally?]
  - review and inform future plans
- Project developments / objectives
  - milestones and measures [as currently]
  - with consent, collate baseline information from attendees on health indicators, budget allocation
  - monitor and review the progress and change made by attendees across the project against baseline
  - compare progress in sustainable project provision against local maps of existing provision
  - share and compare with local services/partners
  - review and inform future plans
- Objective review
  - evaluate against broader measures using external frameworks to offer ~ using for example, Health Equalities determinants (HEF), Quality of Life indicators or the frameworks from Raising Our Sights '*How-to guide 11; Commissioning*' (PMLDnetwork/Mencap, 2013)]
  - review locally and inform local future plans

## 9.7 Funding for a secure future

Meeting the needs of this population will always be expensive (Mansell, 2010) firstly because they require such high levels of support to be able to function and participate in their lives effectively. They may also need specialist facilities and any number of reasonable adjustments and adaptations to be in place [physical, social, environmental and otherwise] to be able to lead an 'ordinary life' as we do, let alone to be truly included in their local communities. Secondly, because people with PMLD are a minority group in our society, their low incidence means there are no economies of scale in authentically personalised provision or services.

Despite this, Mansell also valuably states that 'good provision' costs no more than inadequate or inappropriate provision – so we can, at very least, ensure we secure the best outcomes for individuals, as well as best value for money from the services we currently have. In such a time of austerity this is of significance and will benefit from creative measures to counteract such tension within already stretched budgets.

In order to continue to be viable and to become sustainable, the project is now at a pivotal stage as the GSTC funding has ended. The full economic costs of the Carousel Project providing their programme cannot presently be met by individuals with PMLD as their current funding packages do not reflect real costs. Due to a lack of economies of scale, the full costs of managing this service and facilitating the current programme of activities is prohibitive without further subsidy or some costs being off-set for the project. Financial support is essential to maintain the current programme of activities. Additionally as the project profile has been raised, consideration is needed to respond to increasing demands from the Lambeth population and those with PMLD who live further afield. The management role of setting up and establishing a larger programme will present new challenges. Finding additional fully accessible community facilities may require widening the scope to neighbouring boroughs and their local venues and amenities. All future steps for the Carousel Project to continue, will require substantial funding.

This evaluation was not able to ascertain the status of each individual's Personal Budget or Individual Service Funding, however many respondents highlighted shortfalls both in receiving funding, but also in support and care plans that did not accurately reflect the true costs of meeting needs with appropriate services such as the Carousel Project activities. It was noted also that some carers were reticent to raise this deficit for fear of further cuts to their already limited funding. Most reported they would have benefitted from key-working approach, or 'care navigators' who advocate to support and advise them (eg Leicestershire NHS Trust, 2013).

There is a future need to explore Personal Budgets/Individual Service Funding and how they relate directly to

- detailed individual support plans reflecting aspirational outcomes
- appropriate provision for people with PMLD
- full economic costings [eg travel costs and travel time, support costs and activity fees]

## 9.8 Adding value to local services and a more inclusive Lambeth

A key finding from this evaluation offering great future potential was the 'added value' to local services, from involvement with the Carousel Project. GSTT healthcare professionals and a number of local social care providers offered their strong backing and professional views to evidence the positive impact and highlight this 'added value' to their own service or discrete provision. The reciprocal partnership working between these bodies and the Carousel Project led to more integrated service provision and improved outcomes for all. For example, physiotherapy colleagues described the complementary benefits and enhanced outcomes through the Carousel Project's role to deliver therapy programmes alongside them as specialists, but also the project's ability to continue the programmes and monitor individuals between the block intervention approach of this physiotherapy team. These professionals highlighted further benefits; being able to see a greater number of individuals from their caseload and on a more regular basis than usual current practice allows.

The partnership working facilitated by the Carousel Project approaches enables a more joined-up, person-centred and coordinated approach to services, embodying the current agenda for more integrated services; *'The intent of many integrated care projects is to provide a care pathway that is more focused on the holistic patient experience and care outcomes, rather than on the care provided by any particular health or social care team'* (NHSproviders.org, nd). This potential future direction offers great possibilities to a more sustainable future for the Carousel Project but ultimately to improving the health and lives of people with PMLD in the longer term.

Should the Carousel Project pursue involvement in an integrated services model, then the probability of improved local awareness of people with PMLD and their needs would increase. This may potentially lead to a greater commitment to this population by commissioners, senior leaders and managers to ensure all of their services reflect a truly inclusive and equitable model. The additional benefits could be financial, improve efficiency or have practical outcomes, for example, off-setting the greater costs of services for people with PMLD [due to economies of scale] or, perhaps in service managers ensuring consistency of support staffing by reflecting this need in shift patterns. In order to work in this way, further local collaboration and secured financial support would be required.

Foundation Trust Network (2014) in recommendations on the Better Care Fund [BCF], suggest a number of essential actions [and rationale] to ensure improved access to integrated care. These ideas could support funding applications for the Carousel Project. They suggest in the short term (for transition or change): funds for providers [significant extra investment is needed], provider engagement in the process [they have indispensable knowledge and capability to deliver innovative solutions....the most effective local plans will be those that arise from collaboration], planning processes should be extended; longer term: Government and statutory sector must acknowledge that new integrated models of care take time to establish and need proper investment [new and effective

care pathways requires further investment across the whole system and over a much longer period of time (including a period of double running] (Foundation Trust Network, 2014: 5).

## 9.9 Future innovation and the Carousel Project:

It is vital that the innovation afforded by this unique and effective project, as evidenced by this evaluation, is acknowledged for its leading-edge model and approaches.

The Carousel Project offers an inspirational model of delivery and of good practice to

- act as champions for people with PMLD [locally and nationally]
- raise the profile of people with PMLD and positively influence the expectations of service providers
- meet the needs and improve the lives of people with PMLD and their families
- create responsive, relevant and meaningful opportunities for people with PMLD
- provide opportunities and support to train and develop the wider workforce – with the potential for income generation
- establish and sustain high quality local provision for people with PMLD
- positively influence a more inclusive local community, increasingly with fully accessible amenities
- extend the good practice and provision by sharing the model beyond Lambeth - with the potential for income generation

The Carousel Project has been given strong endorsement by being showcased as an example of good practice through a video exemplar as part of a Department of Health commissioned suite of materials (Mencap/PMLD Network, 2013a). The *'Raising Our Sights, How to Guides'* comprise a set of resources for commissioners, professionals and families that demonstrate *'what good looks like'* for people with PMLD, as a direct response to Mansell's (2010) recommendations.

Investment now in the Carousel Project will be a valuable investment for the future ~ a long overdue investment in the lives of people with PMLD and their families from Lambeth ~ and beyond.

### **A final comment**

***If my family depends so heavily on Carousel despite our 'PMLD member' being somebody who can be taken around relatively easily in the local environment, we have to recognise how absolutely crucial Carousel must be to the families/carers of other Carousel clients.***

Family carer

## 10. REFERENCES

- Broach, S. (2015) Five headline changes in the Care Act 2014. *rightsinreality* blog [Retrieved: 26.8.15  
<https://rightsinreality.wordpress.com/2015/03/31/five-headline-changes-in-the-care-act-2014/>]
- Chadwick, D *et al* (2015) Knowing when I'm sick and helping me stay healthy; views of families of people with profound intellectual impairment. Keynote at Promoting inclusion, communication and wellbeing with people with learning disabilities conference. WIDeN, University of Wolverhampton. 16 September 2015 Wolverhampton Intellectual Disability Network (WIDeN)
- van Dooren, K., Dean, J. Boyle, FM, Taylor-Gomez, M. and Lennox, N. G. (2015) Consider the Support Worker in the Role of Health Assessments. Letter to editor. *Journal of Applied Research in Intellectual Disabilities* (pp1-2)
- DRC/ Department of Health (2007) A National Framework for Disability Equality Etiquette Learning (DEEL) for health and social care services.
- Department of Health (2009) Valuing People Now: A new three year strategy for people with learning disabilities. London: Department of Health
- EuroQol Research Foundation (2015) EQ5D. [Retrieved 6 April 2015 from <http://www.euroqol.org/home.html>]
- Fergusson, A and Byers, R (2015a) Recognising progress – assessing outcomes for young people with severe and profound learning difficulties. Chapter in Lacey, P, Lawson, H, Ashdown, R and Jones P. *The Routledge companion to severe, profound and multiple learning difficulties*. London: Routledge
- Fergusson, A. Howley, M. Rose, R. and Allan, R. (2015b) Hidden behind a label, an uneasy relationship between mental health and special needs. Chapter in Lacey, P, Lawson, H, Ashdown, R and Jones P. *The Routledge companion to severe, profound and multiple learning difficulties*. London: Routledge
- Fergusson, A, Howley, M and Rose, R (2008) Responding to the Mental Health needs of young people with PMLD and ASD: Issues and challenges. *Mental Health and Learning Disabilities: Research and Practice* Vol 2, No. 2, October pp240-251
- Foundation Trust Network (2014) The Better Care Fund: The NHS Foundation Trust view on the impact of the Better Care Fund. Member Briefing: Spring 2014
- Goldbart, J (2015) The role of communication in the quality of life of people with profound intellectual impairment. Keynote at Promoting inclusion, communication and wellbeing with people with learning disabilities conference. WIDeN, University of Wolverhampton. 16 September 2015 Wolverhampton Intellectual Disability Network (WIDeN)
- Gurney, J (2011) Linking lives: communication and connection for people with profound learning disabilities. *PMLD Link*, 23: 1: 68, pp26-28

Harflett, N., Turner, S and Bown, H (2015) The impact of personalisation on the lives of the most isolated people with learning disabilities A review of the evidence. Bath: NDTi

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. and Russ, L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final Report Bristol: Norah Fry Research Centre.

Health and Social Care Information Centre [HSCIC] (2015) Measures from the Adult Social Care Outcomes Framework, England - 2014-15, Final release. Retrieved 8.10.15 from: <http://www.hscic.gov.uk/catalogue/PUB18657>

Lambeth Mencap (2012) Funding application to GSTC. 26.9.12 [unpublished]

Leicestershire NHS Trust (2013) Leicestershire NHS Trust, 2013

McLean J. & McNeice V. (2012). Assets in Action. Glasgow Centre for Population Health. Glasgow.

Mansell, J. (2010). Raising our sights: services for adults with profound intellectual and multiple disabilities. Kent: Tizard Centre

Mattingly, M and Swift, P (2009) A life in the community. An action research project promoting citizenship for people with high support needs. London: FPLD

Mencap/Lambeth Mencap/ I Count (2010) Lambeth PMLD Project: Understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth. Mencap: London

Mencap/PMLD Network (2013a) Video for Raising our Sights: How-to guide 9; what people do in the day. [Retrieved 12 April 2015 from <https://www.youtube.com/watch?v=-8kDzellSgc> ]

Mencap/PMLD Network (2013b) Raising our Sights: How-to guide 11; Commissioning. [Retrieved 2.7.15 from: <https://www.mencap.org.uk/about-learning-disability/information-professionals/pmlD/raising-our-sights-guides> ]

Mills, K (2015) Friendship. A guide to finding friends and building community. Centre for Welfare Reform, in association with Leaf. Available to download from: [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

NHS Providers (no date) Integrated Care. [Retrieved July 2015 from; <http://www.nhsproviders.org>]

Parry-Hughes, R (2011) Friendship Matters? PMLD Link, 23: 1:68, pp15-17

Pawlyn, J. (2013) (2013) Raising our Sights: How-to guide 4: Health [Retrieved 2.7.15 from: <https://www.mencap.org.uk/about-learning-disability/information-professionals/pmlD/raising-our-sights-guides>]

Pawlyn, J and Carnaby, S (2008) (eds) Profound Intellectual and Multiple Disabilities: Nursing Complex Needs. Oxford: Wiley-Blackwell

Petry, K., Maes, B., and Vlaskamp, C. (2009a) Psychometric Evaluation of a Questionnaire to Measure the Quality of Life of People with Profound Multiple Disabilities (QOL-PMD). *Research in Developmental Disabilities: A Multidisciplinary Journal*, 2009, Vol.30(6), p.1326-1336

Petry, K., Maes, B., and Vlaskamp, C. (2009b) Measuring the Quality of Life of People with Profound Multiple Disabilities Using the QOL-PMD: First Results. *Research in Developmental Disabilities: A Multidisciplinary Journal*, 2009, Vol.30(6), p.1394-1405

PMLD Network; <http://pmlidnetwork.org/>

Postural Care Action Group (2011) *Postural care: protecting and restoring body shape*. London: Mencap

Public Health England (2013) *People with Learning Disabilities in England 2013*. PHE publications gateway number: 2014558 London: Public Health England

Qualification and Curriculum Agency[QCA] ( 2009) *Planning, teaching and assessing the curriculum for pupils with learning difficulties :General Guidance*. London: HMSO

Qualification and Curriculum Development Agency [QCDA] (2011) *Assessing pupil progress using the P scales*. London: HMSO

SCIE (2015) *Co-production in social care: What it is and how to do it*. SCIE Guide 51. [Retrieved 28.10.15 <http://www.scie.org.uk/> ]

Thurman, S (2011) *Is communication a human right for people with profound and multiple learning disabilities?* PMLD Link, 23: 1: 68, pp10-14

Te Pou (2013) *Valuing and supporting disabled people and their family/whanau. A literature review and gap analysis of the 'high and complex needs' workforce training needs*. Auckland: The National Centre of mental Health Research, Information and Workforce Development.

Turner, S and Giraud-Saunders, A (2014) *Personal Health Budgets: Including people with learning disabilities. A think local act personal publication*: NDTi

UK Learning Disability Consultant Nurse Network (2013) *The Health Equalities Framework (HEF)*. Developed with iHAL and NDTi. Bath: NDTi

World Health Organisation. (1992) *ICD-10 Classification of Mental and Behavioural Disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organisation

# Appendix 1

## Carousel Project objectives as proposed to GSTC funders:

**By providing access to increased levels of physical exercise and activities, the objectives of the project and the changes we expect to see are:**

### **1. Improved access to sustainable services for people with PMLD:**

- a) Clearly established numbers and up-to-date database of people with PMLD and their needs
- b) Fewer barriers to using mainstream health and leisure activities, such as discrimination, prejudice and low expectations from services.
- c) Raised profile and awareness of this historically-overlooked group of people and their family carers, to bring about a shift in commissioning and planning.
- d) Mainstream and specialist services/activities mapped, and made available and accessible to people with PMLD, and barriers removed.
- e) A Local PMLD network and on-line resources in place and accessible for the families and carers of people with PMLD to use.
- f) People with PMLD and their families, as members of the community, involved in shaping their own health services, by contributing to the design and delivery of a creative new project.

### **2. Health improvements for people with PMLD:**

- a) Reduced serious episodes of ill-health, such as chest infections/pneumonia.
- b) Better postural care, resulting in protection of body shape, and less likelihood of long-term physical deterioration for people with PMLD
- c) Better mental well-being, and improvements to general mood and levels of frustration.
- d) Reduced numbers of in-patient stays for people with PMLD
- e) Clearer routes to appropriate budgets firmly established for people with PMLD, using self-directed support, and raised expectations for this group and their families.

### **3. Health Improvements for Family Carers of people with PMLD**

- a) Reduced episodes of depression and mental ill-health
- b) Reductions in levels of stress/anxiety
- c) Reduced levels of social isolation
- d) Raised expectations for families, who will be able to draw down increased budgets to better meet the needs of the person they care for.
- e) Improved quality of life for the whole family

Lambeth Mencap, September 2012

## Appendix 2

### A selection of stakeholder views illustrating positive change in the people with PMLD attending Carousel Project activities:

#### 1. Postural care

Family carer: after being out of his wheelchair for 'regular stretches' when attending swimming and the dance and movement sessions for a period of several months – *'(he) can straighten out much more'*

Support worker: every week (in dance and movement session) *'he does this long sitting on the floor - and that means he can use his hands more. He's started picking up balls and using two hands together, it's great! But such progress ...started picking up cups and his glass too!'*

Carousel staff: *at the end of the sessions, 'from being out of their (wheel) chairs, most people look so much more relaxed and contented – you can see by their faces and their bodies, they're more chilled out'*

Support worker: *'swimming is good for her - makes her body relax – you can see it ... happening – she is happy. So stiff if no swimming'; 'her posture, gait and mobility are all improved. Her muscle tone is also changed. Her default was always tense, so learning to relax has had an enormous impact'*

Support worker: of rebound therapy – *'she liked bouncing – seemed to loosen her up – getting out of her chair is really good thing. Now she rolls about a bit before (the stretches)'*

New Family carer at taster session - *'Great there was space to get out of the wheelchair - hard at home to stretch her out properly except on her bed...lovely room – warm and just right'. (Mother remarked her daughter had really enjoyed the taster session, I asked, 'how do you know?') ~ 'she is very relaxed & she only relaxes if she feels comfortable, otherwise she gets very very tense and her arms and legs all sort of ... stiffen ( demonstrates); she's been smiling and talking to him (Danny, Carousel staff) – she clearly likes him!'*

Healthcare professional's observations on the general opportunities created by the activities: *'Attendees especially benefit from the movement group and the water-based sessions where the person is able to receive input for physical maintenance programs that it would not be reasonable to expect aging family carers to do. The maintenance of mobility, posture, range of movement, and respiratory status are just some of the benefits of these sessions which have a significant impact on peoples' health needs'.*

Carousel staff: *'her balance has improved'; 'he has a challenging body shape from dislocations – even for the physio. Now there is closer monitoring and more of it (by Carousel and physios combined) – so postural management is better'.*

Carousel staff: when discussing the support and advice they receive from local GSTT team for new service users joining dance and movement activity~ *'when someone new...get physio in to assess – then develop programme for the weekly session'*

## 2. Activity levels

Some examples:

Support worker: commenting on swimming session *'water is so good - it helps him to move without help – no chair. When we get home he wants to move around - more than usual'*. After the dance and movement session (he is) *really active'*.

Carousel staff: of two women she mentions *'(they) move more easily around (walking with support) in the building – more confident – and for longer... (they) just stand up now – dance in the sessions' (with support)*

Family carer: of her sight impaired daughter *'she now moves around the building with a confidence no one can quite believe. She follows voice and uses her indoor cane appropriately'*.

Home manager: *' She used a hoist (originally) to transfer herself into the swimming pool but now - is able to walk down the steps... (she) is walking much better and is able to climb the stairs with support (at home).'*

Carousel staff: *'(she) has restricted movement and limited reaching – but very motivated by the ball in the pool – will reach for a ball or push it through the water'. '(she) is often reluctant to move or go to the bus – [we] now walk to the bus together – important part of the holistic session – now it's fun!*

## 3. Opportunities for communication

Some examples:

Support worker: Quite recently he had noticed the person he supports *'would express her excitement, join in with the singing or even play the guitar. I also started to notice her interacting more with staff members'*. (At times when she is finding it hard to cope) *'she will leave the room for [a] few minutes and then quickly rush back in, which indicates that she doesn't want to miss out'*.

Family carer: *'She now has... unique way of indicating to (support worker) when she is ready to move somewhere. She simply grabs his hand and pushes it forward over her shoulder. In this way it's almost as if she is directing him'*.

Home manager: when talking about the impact of attending Carousel sessions for a person she supports *'(her) interaction with staff has improved her social skills and (she) is communicating in a relaxed manner'*

## 4. Levels of engagement

Some examples:

Support worker: *'she likes to be involved'* – the support worker described how this person did not always join in in expected ways, for example, holding or touching the parachute like the staff rather than underneath it like the others in the session. She preferred to have an 'important job' and particularly enjoyed giving out and collecting activity resources to group members.

Carousel staff: talking about the same young woman, she explained they encouraged her to have some control and sense of responsibility. By supporting her to take a 'leading' role, such as handing out or collecting the musical instruments, this kept her interest and engagement whilst others might be working at a slower pace.

## **5. Emotional wellbeing**

Some examples:

Carousel staff: when talking about raised anxieties potentially created by the lack of structure to their week and/or the frequent staff turnover experienced by many people who use Carousel activities - *'Knowing the big picture (of their lives) is so important- huge amounts of change and uncertainty in their lives'*

Home manager: when giving views on the perceived wellbeing in a number of people they support relating to Carousel activities– *'Saturday Stories ... have been widely attended by 5 people we support. They have really enjoyed these sessions ... a chance to do something new and engage in an enjoyable activity. Dance and Movement ... has been attended and enjoyed ... they got a lot out of the sessions. Rebound Therapy... was attended by a number of residents and massively enjoyed'*.

Support worker: *'(he) arrives quite positive...likes the dancing and spinning round in the space ...enjoys the circle-time and really, really loves walking around 'saying hello' ~ (gestures 'greater') confidence and huge improvements'*

Speech and Language Therapist observation (via support worker feedback): *'(he) is more communicative here than anywhere else ... different responses to home – motivation!'*

Family carer: sharing the positive progress of her daughter who has needed two years to become familiar and trusting enough to join in the Saturday Stories sessions – *'...their routine is finely tuned now, which has enabled (her) to cope so much better ...Everyone has commented on this huge increase in her confidence....accompanied by a significant reduction (in) her distressed behaviours...She always makes it for the 'goodbye song' and as time passes is able to tolerate the session much longer...'*

Home manager: commenting on the changes in anxiety levels and engagement observed in a woman they support with a dual sensory impairment, *'in the five years I have known (her) this is the first time she is enjoying activities .... in a relaxed and positive manner (she) is happy to participate'*.

## **6. Social inclusion**

Some examples:

Support worker: talking specifically about positive progress of the person she supports particularly when working with Danny and Bernal (Carousel staff) ' such good interaction ...and eye contact – a good amount of time too – exciting to see it develop!'

Carousel staff: suggested they have a 'criteria' for anyone new joining sessions ' a bit of an 'assessment' – for harmonious dynamics of the group – it's very important it works'

Family carer: highlighted the importance of reciprocity from the developing relationships she has observed through the Carousel sessions, compared to the more solitary and isolating alternatives of solely 1:1 experiences of the day to day at home or with one PA. The benefits of this 'sense of community' included her, as a parent, who felt 'very isolated as a family'.

Support worker: highlighting some of the 'best bits about Carousel' for the young man she supports '(he) arrives quite positive ...sometimes quite vocal ...very aware of others, especially (another Carousel attendee) – great social opportunity we don't get anywhere else'

Carousel staff: when discussing the social aspects of the Carousel work, described subtle changes by individuals and from the activity groups as a whole 'recognising each other...sense of belonging to (a group) ...like Saturday club – observe a growing awareness of it – support workers too –they notice changes in other service users, not just theirs'

Family carer: 'belonging to a group – each one of them at the centre session... all benefitting (a) great deal – she can be herself, people admire her for this and encourage her to do what she wants and when she choses'

Support worker: 'now when we arrive...she rushes through the door and is often excited when greeting staff. She loves to engage with her favourite staff members who always make time for her one to one sessions of "catching up".'

Support worker: of the person he supports whom he viewed previously to be very isolated 'the Carousel Project ...provides her with a platform to evolve her social life and engage with others and society'

Family carer: on her daughter's involvement with Carousel '...provide social contact and friendship with a local peer group with which ... (without Carousel activities her daughter) would lose touch completely'; 'a project that offers on at least four days a week ...consistent interesting and 'appropriate' sensory activities for entertainment, interaction, communication and cognitive development facilitated by staff members who ... have become 'skilled up' ... (in their) Carousel clients'.

## Appendix 3

### Examples of views relating to the support workers' involvement in Carousel Project activities.

Carousel staff: on the importance of consistency of support worker attendance during the last discussion of the evaluation '...now seeing the harvest of time - where the same people are coming'.

Two support workers: that day was their first time at a Rebound Therapy session –one of them had discovered she was attending when she arrived on - and literally minutes before the transport arrived. Both workers were concerned they would need to get on the trampoline. She asked '*what's all this about then?*' and commented '*she (the person with PMLD) doesn't see - she won't like it.*

However at the end of that first session, she offered a different picture view, commenting how valuable to observe their service users being supported by in unfamiliar activities. Both workers noticed 'new' responses from the two people they support;

Support worker 1: '*(she) looked really relaxed, liked the bouncing ... loosened up; maybe add some music to help relax more – she likes Calypso*'

Support worker 2: '*getting out of their chairs – really good thing. Be better for (her) to go on (the trampoline) and roll about a bit first – before them stretches ... definitely see she's relaxed now - look at her laughing*'; She commented on the relationship between the person she supports and Carousel staff supporting her on the trampoline '*...good amount of one on one time with Bernal – interaction, eye contact – that's good for her, not usually so interested*'.

Support worker: explained coming to the hydrotherapy session she was very embarrassed at first and not particularly confident in the water, but now she regularly supports the person at this session she felt she gets a lot of benefits herself from attendance. When asked to explain '*many things – seeing (her) communicate with people – (points to the pool) it relaxes me too – makes me happy too*'; *helps me too – know how to support her in the water – and move her too*'.

Support worker: At the end of his first visit to the hydrotherapy session the carer was asked if there were any benefits for him in his professional role from attending the Carousel activity, '*Interesting to see the facilitators interact with (person he supports) – that's a real benefit already – see the expertise from a well-known organisation. It's not just for (person) it's for carers too – we (??) actively involved – and physios here – that's excellent*'.

Support worker: regularly supports a woman at several Carousel activities. She offered examples of benefits to her role '*I can share feedback on it with Mum – important, (she) likes me doing that too – important*'. She described how she has now transferred some of her learning from the activities at home '*every morning I do 25 minutes of her exercises – and we sing – the songs she knows from here – she likes that*'.

This support worker was observed on another visit [towards the end of the evaluation cycle] confidently 'taking the lead' with the person she supports during a rebound therapy session. Her professional skills and confidence had evidently increased and she even assertively suggested some more suitable ways to enable the person she supports to '*stretch out* better'.

Carousel staff: described some of the approaches they used to involve and motivate support workers to get involved eg at the start of every Dance & Movement session they tell their individual service user what they're going to do. He models from the front how the support workers demonstrate a 'keep fit' sequence in front of the person with PMLD. He explained this motivated the support workers and 'warmed *them* up' ready to start the session. He emphasised the importance of feedback and encouragement for these professionals, to increase skills and confidence.

Carousel staff: explained how having a familiar structure to every activity session was helpful to support staff as well as to the people with PMLD. This approach raises the awareness of support workers to what the benefits are for the service user [of the activity] and why they are there; they begin to see concrete benefits for themselves. '... they start to know what to expect and what to look for – some notice changes in other service users too. The structure encourages everyone'

However not everyone saw this approach as meaningful to them [as support workers]; some support workers described elements of the sessions as 'boring' or 'very simplistic' because they were always the same.

Yet another support worker actively praised the importance of this predictable sequence of events, noticing because of the familiarity the person he supports was recognising the songs, but also seeing other attendees 'beginning to anticipate by turning their head towards the music...smiling and vocalising'. He was able to see this increase over time.

At the end of every activity, support workers are asked to record their feedback on that session for the person they support. The aim of this is to monitor progress and change in the people with PMLD but as importantly to influence and personalise the planning of future sessions. Some support workers find this difficult.

Carousel staff: 'confidence varies a lot... all sorts of reasons, sometimes because they are new or don't know what to look for [in the person with PMLD]'; 'sometimes its literacy or language problems – they're not all English speakers, or not confident anyway... puts some off coming I think'. On the feedback itself, 'Sometimes what you get is very limited or not even useful – hardest part of the sessions maybe?'

Support worker: She felt comfortable to say what was not working for the person she supports in the Carousel activities, 'he's not too interested in the parachute ...but tell them at the end of the session [on a form] – about his responses'.

Home manager: talking about Rebound Therapy sessions 'made me read up about it – really interesting health-wise – didn't know [about Rebound Therapy]...now I've seen it for myself'.