



## **Allied Health Professional case studies: Living with a disability**

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**Evaluating the Impact of Music Therapy for Children with Dementia**

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**The Get Going Group: dramatherapy for people with learning disabilities and mental ill health**

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## Sport for Confidence and Stay Connected: Creating an online physical activity service

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### Description

Sport for Confidence CIC is a unique and innovative organisation, which brings together occupational therapists and specialist sports coaches to provide activity-based assessments and interventions for marginalised groups across Essex. Sport for Confidence typically operates within leisure centres, but during the coronavirus pandemic the Stay Connected service was created - an online service that utilises occupational therapists and sports coaches to provide support to marginalised populations, such as disabled people and people living with long-term conditions.

### Context

The Stay Connected service enables participants to access and engage with a wide range of online interest groups, low and high intensity physical activity groups, and vocational groups. The occupational therapists enhance this offer by providing additional telephone contact, occupational assessment, active listening, empathy and personalised advice. The service also works in partnership with care and community providers to enhance resilience and accessibility of existing provision, supporting them to develop and embed sustainable and inclusive online solutions.

The Stay Connected service was originally commissioned in April 2020 for 6 months, to offer immediate support to disabled people living within Essex due to the pandemic. The service proved successful, and an extension was granted. Stay Connected is a person-centred service, which focuses on meeting the needs of individuals who face barriers in initiating, accessing and sustaining contact with support services. This is because these individuals are often the most at risk of experiencing a deterioration in their mental and/or physical health, exacerbated by the requirements to socially distance, shield and/or self-isolate. These individuals are also known to encounter inequalities in sport and physical activity participation, which has consequences for their health and well-being (English Federation of Disability Sport, 2013; Sport England, 2016). The service recognises the broader context of people's lives and how this relates to their health and well-being. Therefore, assessment and support is also offered to those in a caring role (whether paid or unpaid) to reduce the risk of carer breakdown. This further supports national policy that seeks to enable people with health conditions and impairments to live an active lifestyle (English Federation of Disability Sport, 2016).

## Method

The service started with telephone and email contact and developed to providing regular Zoom exercise classes alongside occupational therapy assessment and support. The following demonstrates key stages in the service improvement:

- Started with a basic service telephone and email contact service
- Awareness raising sessions (live social media events, providers and health and social care workers)
- Strengthen existing and new partnerships and referral pathways (e.g. Enhanced Social Care Support for Adults with LD/Autism team).
- Reviewed and changed measurement to qualitative data collection only to enhance rapport building and connection with the member of staff.
- Gradually increased and adapted the offer to include: personalised support ranging from, a short phone call to regular and lengthy contacts subject to needs assessment, signposting, email contact, personalised physical activity videos, zoom sessions, resources sent/recommended.
- Posted infographics of monthly contact via social media
- Provided a weekly zoom timetable
- Co-created resources with Team Create (includes participants with lived experience of disability/mental health/LD) to use within sessions (e.g. 'How to start a conversation about PA')

## Outcomes

- The service was initially measured using self-rated measurement tool but feedback from the participants led to qualitative measurement, using feedback and case studies.
- Total referrals April 2020 – Feb 2021: 1157
- Current Caseload as of 1<sup>st</sup> March 2021: 129
- Total Zoom sessions delivered for January 2021: 41
- Total Zoom sessions delivered for February 2021: 41
- Total attendance at Zoom for January 2021: 576 interactions (average attendance of 14)
- Total attendance at Zoom for February 2021: 668 interactions (average attendance of 16)
- Average 0 – 10 rating given by participants on service provided: 9.7

There are many examples of what has changed, including:

- **Increased access to physical activity** (e.g. 5 days a week rather than 2x week in prior to covid)
- **Challenged assumptions** around people with a learning disability/Autism using digital platforms, we have enabled participants connect with new and old and stay connected with all.
- **Increased opportunity** for people to make independent choices about what activities they want to join. A choice of 14 different sessions a week was something that was not previously an option for the majority.
- Enabled participants to **safely try different sports and activities** they may not have tried before- enabling us to grade their exposure online and work towards them trying new things face to face in the future.
- Provided participants with **structure and routine**

**Client feedback:**

*"This service has been helpful / useful by just knowing they are a phone call away in this difficult time of lock down uncertainty... keep up your amazing work! I am grateful to you all for your help and support and the belief you all have in me to achieve and grow as a person".*

**Family feedback:**

*"My son has Down's syndrome and attends a Sport for Confidence session; the therapists have kept these going each week via Zoom. This has allowed him to keep in touch with everyone, which given his additional needs he would not have been able to do... the variety of activities is great... the care and attention put in by the therapists is outstanding".*

*"Everyone at SfC has been amazing, all the team are so caring. My son is a completely different person since participating in the Stay Connected service."*

**Carer Feedback:**

*"The team have made me feel part of the 'outside world indoors" Thank you.*

**Provider feedback:**

*"We have been given lots of suggestions and physical activity information. Our client has now been offered a fantastic Video Carephone thanks to Stay Connected and they have been supporting one of our clients regularly".*

The extension and how the service is evolving suggests the service is respected and valued by the commissioners who want it to remain. The consistent number of referrals suggest the service is of value to health professionals and participants.

## Key learning points

- Learning to evolve with time and acting quickly, Covid has been a roller coaster ride and we have had to exhaust all our innovative creations to ensure that we can adapt to support the participants at their own pace.
- A single point of access has been a real important learning experience, something extremely valuable and as a consequence results in participants gaining efficient, sensitive and consistent support.
- Technology is difficult to navigate, however, it can be done with attention and care.
- The iterative approach we have taken has enabled us to adapt and change our approach as we go, therefore we have consistently followed check, challenge and change principles.
- It's clear there is a long term need for virtual and face to face delivery, to promote choice and independence for participants.
- To explore how this service becomes a long-term plan as part of Sport for Confidence and the participants we see.

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## Evaluating the Impact of Music Therapy for Children with Dementia

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### Description

Batten disease, a rare neurodegenerative condition, currently affects around 200 children in the UK. Children experience gradual loss of sight, speech, understanding, memory and mobility, and the disease causes shortened life expectancy. Care pathways for children with this disease, are focused on isolated symptom management, and a more holistic, pre-emptive approach to care, therapy and education is needed. Current research into therapeutic care is limited for this population, yet there is emerging evidence suggesting benefits of music-based interventions. This project aimed to ascertain the benefits of music therapy on the key functional areas of cognition, speech, and movement to improve health outcomes for children affected by Batten disease in the UK.

### Context

Principally, healthcare research for children with Batten disease is currently focused on curative pharmacological interventions and the care pathway is largely focused on symptomatic management or palliative care solutions (Augustine, Adams, & Mink, 2013). This means many families and children living with Batten disease, lack consistent support in terms of care and education and many feel they must navigate their own pathway of care when they need help (von Tetzchner, Elmerskog, Tøssebro, & Rokne, 2019). Unpredictable deterioration can create anxiety, psychological distress and trauma for affected children and their families, yet formal recommendations for wellbeing activities are non-existent for this population.

Emerging research has demonstrated the positive influence of pre-emptive education strategies and the significant impact that music can have on a child's wellbeing (von Tetzchner et al., 2019). Incorporating pre-emptive teaching into a child's education and therapy curriculum could help anticipate difficulties or challenges experienced later in a child's life (for example introducing Braille skills, cane and orientation skills, speech activities or independent mobility aids). As yet, research into music and wellbeing activities are non-existent, and this project, therefore, aimed to address this gap in knowledge in order to guide families and professionals supporting children with the disease.

### Method

The three-year project observed children with Batten disease in weekly music therapy sessions. Drawing upon assessment measures from both the clinical and music therapy domains, the project explored how functional skills in music therapy could change over time in comparison to standard clinical assessments, in order to improve wider health outcomes for affected children. Data used in this project formed part of a larger study looking into the impact of music for individuals with Batten disease, where ethical approval was granted by the University of Roehampton Ethics board in 2016 (Ockelford et al., 2019).

## Participants

Twelve children with Batten disease (aged between 3 to 18 years) took part in the research, and from the fourteen variants of Batten disease presently known, the children represented five different types. Ten music therapists and one music teacher were involved in the delivery of music therapy and music lessons over the three years.

## Intervention

Children received weekly music therapy sessions over the course of three years primarily in an education setting. Sessions focused on a suggested practical framework to facilitate speech and language, cognition, creativity, movement and wellbeing. The team of researchers made observation visits once every school term and practitioners also sent session videos at quarterly intervals each year for additional analysis.

## Assessment Measures

The standardised Hamburg Clinical Rating Scale for Batten disease (Kohlshutter, Laabs, & Albani, 1988) was used every 12 months to record speech, movement and cognition. In addition, a new bespoke music therapy assessment tool (Chiltern Music Therapy Outcome Measure (CMTOM), Atkinson, 2018 [see appendix 1]) was used to analyse each video recording of children's sessions. To demonstrate validity of the CMTOM measure in the study, validation exercises were carried out to determine appropriateness, relevance, and feasibility of the measure for music therapy sessions. Results from the validation exercise indicated positive results with regards to the reliability (Intraclass Correlation Co-efficiency) and face validity (practitioner questionnaires).

## Outcomes

### The Impact of Music Therapy

#### Clinical Assessment

In all areas of the Hamburg Clinical Scale, average mean scores showed consistent deterioration in the areas of cognition, communication, and mobility. As can be seen in Figure 1, average mean scores ranged 0.4 – 2, and plot lines show a downward deterioration across all domains.

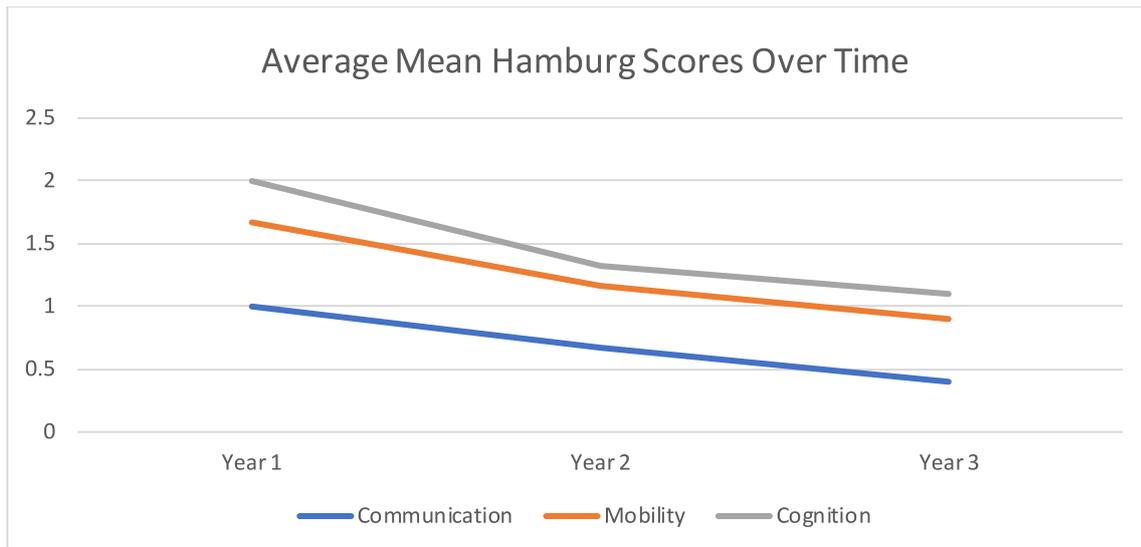


Figure 1: Average Hamburg Scale mean scores for communication, cognition and mobility across 3 years.

### Music Therapy Assessment

By contrast, average mean CMTOM scores showed a different picture. As can be seen in Figure 2, the graph demonstrates a smaller range of scores (1.47-2.83) and a plateau effect occurring in the mid stages of the three-year project (time points 3-13). It was observed that there was a period in music therapy sessions, where children’s average mean scores remained stable, and skills were seemingly maintained.

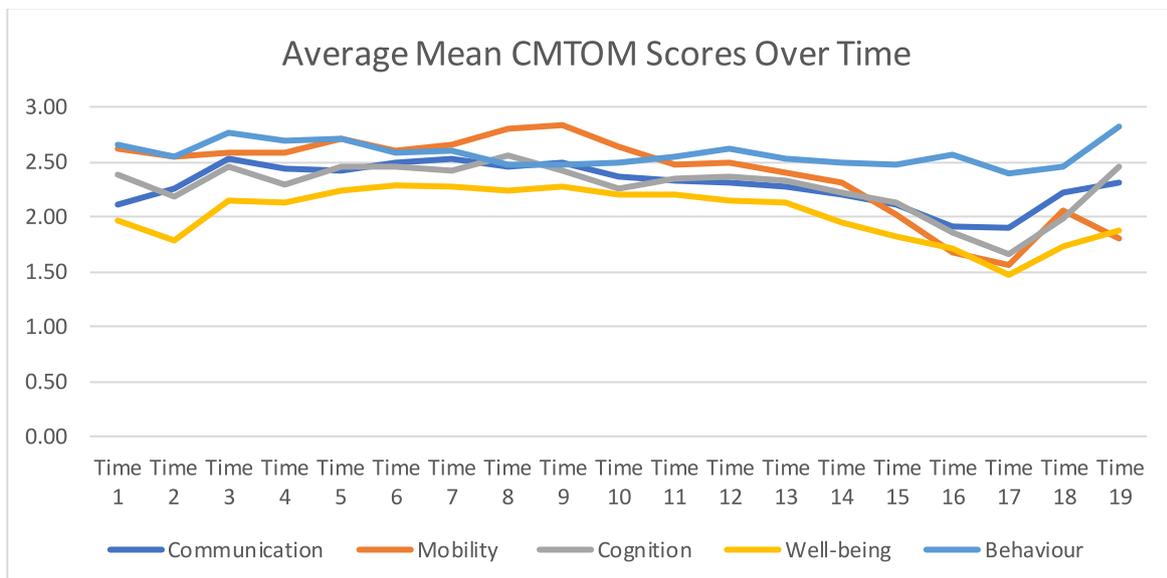


Figure 2: Average CMTOM mean scores in communication, behaviour, emotional wellbeing, cognition and mobility across 3 years.

Results perhaps indicate that a child's skills, within the context of music therapy, deteriorate to a lesser extent than skills measured in a clinical context. The marginal declines and periods of maintained skills in the CMTOM (when compared with sharp declines on the Hamburg scale) suggest that the impact of music therapy could help slow the decline of skills and offer periods of stability. Moreover, marked differences in the rate of deterioration on the Hamburg Clinical rating scale and CMTOM, suggest that a wider understanding of the child's abilities and capacities, can be picked up in a music therapy assessment framework in comparison to the standard clinical test. It could be suggested that without music therapy input or music-based assessment, children affected by Batten disease could be perceptibly deteriorating faster over time, which could significantly impact the approach to their care and education.

## Practical Activities

Observations from the session videos, highlighted key musical activities found to be of benefit to the children. As reported in the full research study (Ockelford et al., 2019) particular activities were found to help support language, memory and wellbeing.

### *Music to support language*

Drawing on the principles of Neurologic Music Therapy (Thaut, 2014), music and language activities focused on scaffolding language in song, rhythm or melody. For example, key meaningful phrases (such as family members' names, preferences, or activities) were formed into meaningful, memorable melodies and songs to help support memory retrieval. Previous parent accounts also support this finding:

"Music was very important – she enjoyed listening and singing. Long after her speech went she was still able to sing or mouth the words to 'Happy birthday'" (von Tetzchner et al., 2019: 348).

"...lyrics came out clearly, even though her speech was so little, stuttering and slow" (von Tetzchner et al., 2019: 348).

Techniques of Music Speech Stimulation (MUSTIM) and Rhythmic Speech Cueing (RSC) were used to help children complete their sentences with prompts or pace their speech with a metronome tempo. To encourage carryover, further research would investigate the carryover of such techniques and whether they could be introduced by teachers or other allied healthcare professionals.

### *Music and memory activities*

Music, songs and melodies were also used to support recall and memory retrieval. Particularly when children were showing symptoms of memory loss or confusion, often music was used to help orient the child i.e., songs for activities throughout the day, or songs for each day of the week etc. This concept was also demonstrated in previous parent feedback:

"Music is used every day. He has special songs to fall asleep to; different songs have been used in different situations (pee song, wake up song, be together song)" (von Tetzchner et al., 2019: 353).

Additionally, practitioners in the research created memory books for children based on experiences, memories, or key pieces of information (i.e. family members). These were multi-sensory in nature drawing upon braille, audio clips, tactile objects and accompanying musical recordings. Professionals reflected on the positive impact of memory books:

“This fully interdisciplinary approach involving music, English, braille, and art was motivating for her and as her disease progresses further, the book will be there to aid her in remembering her favourite songs, through listening to her own voice and by feeling the tactile materials that she has so carefully chosen” (Ockelford et al., 2019:32)

Despite early visual deterioration, sessions also utilised the child’s unimpaired hearing to support choice-making or to indicate preferences. By presenting different instruments in different auditory fields, children were encouraged to use gesture to indicate preferences. With pre-emptive teaching, instruments could be extended to sounds or voice notes, to represent activities, place, or people in order to develop independent choice-making for children for longer. Although further research is needed with regards to these activities, they could be translatable to allied health or education or home contexts to support independent choice-making and enhance quality of life for affected children.

### *Music and wellbeing*

Generally, music was found to help support relaxation, stimulation and comfort, and previous parent feedback supported this concept:

“[Music] really calms him down, and he gets so upset when we try to turn it off.... It really calms him down when he’s agitated or in pain” (Ockelford et al., 2019: 33).

“We usually use music to create a calm, relaxing environment ... but a fast song with a strong beat will usually get her to open her eyes.” (Ockelford et al., 2019: 33).

Using music to support wellbeing is one area particularly transferable to other areas of education, therapy and care, and the simple act of interactive music listening alongside family members of professionals, could significantly enhance wellbeing for children affected by Batten disease.

### *Key learning points*

Findings from this initial research project unearthed many learning points which could have a positive impact on the future care and therapy for children affected by Batten disease. They are summarised as follows:

- There is seemingly a positive impact of the long-term music therapy for a child’s speech, cognition, mobility, and wellbeing.
- Current standard clinical assessment measures for children affected by Batten disease could be limiting and misrepresentative.
- Activities such as memory books, using music to support key phrases, songs for activities, auditory choice-making and music for relaxation received positive feedback from parents and staff.
- Music activities could be transferable to other therapy, care, allied health settings or education contexts to provide a holistic joined-up approach to healthcare and education.

- Parents, families, and caregivers could integrate the music activities outlined here, to enrich interactions in the home environment.
- Future research would aim to develop a systematic and consistent approach to music therapy sessions (i.e., sessions would be delivered by the same practitioner or follow a set protocol).
- Follow on validation exercises would aim to strengthen the validity and appropriateness of the CMTOM for other neurodegenerative patient groups.
- Introducing music-based activities earlier on (before skills are lost) could support children's memory, communication, and wellbeing for longer.
- Ongoing research is needed to explore the impact of specific music-based language exercises for affected children.

Findings from the research will be shared with other allied health care settings, parent advocacy services, and music therapy learning communities in order to improve approaches to education and therapy for affected children. Findings may also be relevant for other paediatric and palliative care settings, other rare or neurodegenerative conditions, and dementia care sectors.

Further research will focus on creating and developing a music therapy program for affected children that is transferable to other healthcare and education settings. Research in this area ultimately aims to provide families, health professionals and educators with music-based activities to enhance wellbeing, increase quality of life, and improve health outcomes for children with Batten disease.

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## Appendix 1 - Chiltern Music Therapy Assessment Tool

The CMTOM was used to assess and monitor developments and changes in relation to music-based skills within the clinical areas of speech, cognition, movement. The CMTOM was by CMT practitioners, with the aim of capturing behaviours and skills in a music therapy session. The matrix is intended for multiple populations, but specifically enables skills to be tracked over time, so that it can be used with neurodegenerative populations. The use of the matrix provided an opportunity for more in-depth and regular analysis of each child within sessions and captured a detailed picture of musical skills (i.e. singing abilities), beyond that which was captured using the Hamburg Scale.

<u>Observations</u>			
	<u>DATE</u>		<u>DATE</u>
<i>0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = consistently</i>	<u>Score</u>		<u>Score</u>
<b><u>1. Communication &amp; Social interaction</u></b>		<b><u>4. Emotional Expression</u></b>	
Appropriate eye contact OR tracking of visual stimuli		Verbal expression of mood	
Appropriate use of gesture		Physical expression of mood	
Vocalisation (any sound)		Musical expression of mood	
Verbalisation (use of speech)		Choice of instrument / art material / object / preference	
Singing		Use of voice/ sound making tools for expressing self	
Awareness of others		Able to tolerate sound(s), art form, types of media used	
Ability to interact non-verbally / verbally		Insight into difficulties & strengths	
Interaction with staff		Ability to explore and discover	
Ability to Initiate interactions		Shows capacity to improvise / free play	
Behaviour / music to therapist appropriate?		Can differentiate between real and imagined	
Notice, tolerate, accept, aware of others		Has enthusiasm, shows pleasure, fun, enjoyment	
Ability to participate / join in			
Sharing emotions, thoughts and ideas		<b><u>5. Sense of Self</u></b>	
Being able to think about others - show empathy		Ability to participate, initiate, choose, lead	
		Shows appropriate level of self confidence	

<b><u>2. Behaviour</u></b>		Is resourceful, decisive and can work autonomously / independently	
Trigger observed to changed behaviour?		Demonstrates appropriate levels of assertiveness	
Any verbal aggression noted			
Any physical aggression		<b><u>6. Cognition</u></b>	
Behavioural response to musical components noted?		Follows verbal instructions	
Ability to express / control self in an appropriate way		Makes choices	
Expression of feelings of distress, agitation, anxiety		Ability to attend to task	
Expression of feelings of depression, trauma, loss, bereavement		Recognition or carry over of previous material	
		Engages appropriately with instruments	
<b><u>3. Physical Presentation</u></b>		Any memory recall noted? (rhythmic recall etc.)	
Active movement noted?		Sustains attention	
Core/trunk stability noted?		Shows interest and is inquisitive	
Head and neck stability noted?			
Use of weaker limbs noted?			
Bilateral (both hands) coordination noted?			
Hand-eye coordination noted?			
Ability to cross mid-line - movement R-L or L-R			
Fluency of gait movements?			
Ability to grip in RH			
Ability to grip in LH			
Individual finger movements noted for use with piano, assistive or music technology?			
Oral motor control noted?			
Breath control and regular respiration noted?			

Hand-over-hand or facilitated movement needed to participate in music making?	
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## Annual Physiotherapy Review Project – Working to create an efficient, patient centered and cost-effective service to those with profound and multiple learning disabilities in the community

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### Description

The Southampton City Community Learning Disability Health Team provide care to those with learning disabilities in the community. Changes within the NHS has led to adults with learning disabilities being open to the team under an 'Episodes of Care' philosophy. This results in service users only being open to the physiotherapy team when the person and, or their family/ support staff notice that there is a problem that needs addressing. Since adopting this approach the Physiotherapy team noted that in many cases service users were referred at a late stage of their current complaint. Late referral results in a person experiencing more complex care needs (e.g. dysphagia risks, respiratory care needs, chronic pain) and increases the support required from NHS services.

The Annual Physiotherapy Review project seeks to take a preventative approach, assessing and documenting changes in condition such as weight, posture, contractures and scoliosis annually. The aim being early identification of deterioration of posture and respiratory care to enable appropriate and timely support to resolve the issue. This approach is in line with NICE guidelines *Care and support of people growing older with learning disabilities* NG96 (2021). The potential benefits of this proactive annual review approach include, reducing risk of, hospital admission, increased care packages and increased equipment needs, whilst maximising the efficiency of NHS work force resources.

### Context

The project developed due to repeat referrals into the Learning Disability (LD) Physiotherapy service with examples of service users requiring new equipment (such as wheelchairs/sleep systems/standing aids) due to late identification of postural changes and or worsening contractures.

The aim of the project was to achieve early identification and treatment of postural and physical health changes in adults with profound and multiple learning disabilities (PMLD) in Southampton. This is important, as respiratory conditions remain the most significant cause of premature mortality in people with learning disabilities (Leder 2020). Poor postural management impacts on respiratory care as scoliosis will impact on rib cage deformity and lung volumes. These individuals are also often

reliant on others (family/paid carers) to recognise changes to tone, contractures and spinal changes due to the level of their communication difficulties. Expressing pain can often be difficult for these individuals and is very often “under recognised and under treated” in those with learning disabilities and there is a misconception that people with a learning disability have a ‘higher pain threshold’ (Doody and Bailey 2007)

There were three primary objectives to be achieved through the Annual Physiotherapy Review:

- Ensure efficiency of service within the resources available
- Create a person-centered service
- Cost efficiency

It is well known and documented that people with learning disabilities are more at risk of deterioration in their health, which forms the basis of the NHS GP Annual Health Check scheme (NHS UK 2021). Heslop et al., (2014) found ‘avoidable deaths from causes amenable to change by good quality health care were more common in people with learning disabilities (37%) than in the general population of England and Wales (13%)’, and that people with ‘more severe learning disabilities have been recognised as having shorter life expectancies than those with mild learning disabilities’.

## Method

The project identified those people in Southampton with PMLD and complex physical health needs who were at risk of late identification of their complex health needs. An original caseload of 49 service users were involved with the project in 2019 (x1 RIP prior to assessment x1 moved out of area).

An assessment form was then designed based alongside the GP LD annual health check and postural care assessments. The reasoning was to identify those with postural needs but also to collect simple health data such as blood pressure and weight, as evidence has shown that GPs have difficulties completing these assessments for people with PMLD due to lack of appropriate equipment, which may then lead to late recognition of deteriorating physical health. This is also in keeping with a ‘making every contact count’ approach.

A detailed 12 page assessment was completed including, but not limited to:

Area assessed	Assessment/Measurement	Notes
Weight	Weighing via sit on or hoist scales	GPs often do not have access to this equipment
Height	Measuring tape with S/U lying on their bed	Where this was not possible an ulna length was taken and converted as per the ‘MUST’ <a href="http://www.bapen.org.uk">www.bapen.org.uk</a>
BMI	Calculation kg/m <sup>2</sup>	
Medication/ Drug charts	Review of medication specifically pain relief and anti-spasmodic	Liaison with GP required
Skin Care	Review of pressure points and high risk of breakdown	Specific assessments around shoulder blades, sacrum and calcaneum
Blood pressure and cardiovascular function	Sphygmomanometer where able Electronic wrist cuff if unable to use sphygmomanometer	An assessment GPs find challenging due to spasticity of upper limbs. Often spasticity is reduced following physiotherapy assessment so easier to access the upper arm to complete

		assessment. Service users often lying in bed also helps aid with relaxation to complete assessment.
Respiratory	Auscultation  Pulse oximetry	Auscultation will consider scoliosis and potential lung fields dependent on individual's deformities.  Use of toes when unable to gain reading via finger.
Physical Disabilities	Use of OCE 'part B' range of movement with 'postural deformities' assessment chart	In line with postural findings: Review of wheelchair Review of slings Review of sleep systems Review of standing frames/walking aids
Pain	Pain noted during assessment at certain joints	As with 'medication' section review pain relief where required

An annual review was completed by a physiotherapist with these service users, discussions were held with family members/support workers in relation to the findings of the assessment and an appropriate care plan was developed with the service user and their main support team.

In 2020, the review was streamlined to a 2 page document in order to make the process more efficient, and sought to assess key subjective and objective information of the service user's condition from the past 12 months.

Assessment	Notes
Changes to health over the past 12 months	Any notable health issues that require escalating
Changes to medication over the past 12 months	Anything that may impact on physiotherapy recommendations
Wheelchair specifications and needs	Any changes noted or required
Sling specification and needs	Review slings for wearing and fraying and replace
Critical measures – specifically changes over the past 12 months	Are ranges of movement reducing over last 12 months and require intervention
Respiratory Assessment	To review service user's baseline respiratory
Weight/BMI	To review any changes and liaise with family/support team or GP if required
Postural deformity chart	To review postural management – specifically sleep systems/equipment needs

Once the assessment had been completed, it was decided whether or not the service user was suitable for discharge, or whether they were referred onto the physiotherapy caseload.

## Outcomes

### Outcome of the assessments:

#### 2019

47 service users were offered an assessment as they met the criteria for the project.

Percentage	Number	Outcome
4%	1	Refused review
27%	13	Already open and receiving physiotherapy intervention
31%	15	Review complete – deemed suitable for discharge
41%	20	Physiotherapy needs identified => referral for physiotherapy intervention It is unlikely these needs would have been identified without the physiotherapy review

#### 2020

45 service users were offered an assessment as they met the criteria for the project

Percentage	Number	Outcome	Comments
16%	7	Refused review	Mainly due to Covid-19 pandemic
15%	7	Already open and receiving physiotherapy intervention	
49%	22	Review complete – deemed suitable for discharge	
20%	9	Physiotherapy needs identified => referral for physiotherapy intervention	x 5 of these the physiotherapy team were already aware of – annual reviews were worked around this. x 4 ‘new referrals’ found previously undetected needs at this time.

### Intervention Identified from assessments:

#### 2019

#### 2020

Number	Referral Reason		Number	Referral Reason
8	Specialist mobility; Standing aids (such as Quest 88) walking aids (such as buddy roamer, Meywalk) etc.		1	Specialist mobility; Standing aids
8	Postural management including sleep systems		3	Transition into adult services
4	Moving and Handling		2	Moving and Handling
			2	Sling reviews
			1	Review of exercise programme
<b>24</b>	<b>Referrals made into the wheelchair service</b>		<b>2</b>	<b>Referrals made into the wheelchair service</b>

## Health issues that have been highlighted through the project

- Weight loss/gain – advice given and x2 referrals to GP/Dietitian
- x1 unexplained weight loss led to further investigations regarding cancer – negative following screening.
- Respiratory assessments have identified x2 chest infections prior to support staff knowledge ensuring timely intervention from GP.
- Poor activity levels secondary to physical disability – x8 service users were signposting to leisure activities to promote more active lifestyles for those wheelchair users who have limited community access to activity.
- Three examples where standing/mobility activities had stopped due to equipment failures and staff unable to work out how to solve this. Support was provided to fix/replace this equipment to re-start these activities – improvements on musculoskeletal, digestion, respiratory and cardiovascular function.
- Reduction of referrals (22 in 2019 to 2 in 2020) to wheelchair services reducing NHS costs and time for clinicians. Also improving quality of life for service users ensuring they are using appropriate seating.

## Key learning points

Offering a proactive Physiotherapy annual review to those with complex physical health needs associated with profound and multiple learning disability and communication difficulties appears to result in earlier identification of postural care needs and earlier provision of equipment to prevent further deterioration of posture. Early identification and support for these needs is likely to reduce the risk of:

- Respiratory conditions resulting in reduced acute hospital admission
- Health conditions, specifically cardiovascular function and bowel management associated with physical inactivity
- Pressure sores
- Pain

## Areas for improvement

Issue	What we have done
Support Staff unaware of historical recommendations	Re-sent recommendations Offered teaching if required
Concerns with lack of 'flexibility' with physiotherapy recommendations	Incorporated recommendations into activities of daily living as opposed to a separate 'activity' such as bathing, dressing etc.
Challenges to complete physiotherapy recommendations such as aquatic therapy, specialist gyms, sitting activities due to: Staffing Finances Transport	Liaison with adult services/CHC to improve issues where able. Negotiated recommendations where these issues were unable to be resolved to reduce pressure on families/support staff.

## What went well?

Positive feedback received from carers and other health professionals:

- “Reassured me that I am doing the physiotherapy recommendations right!”
- “Always feel the staff are supported by the physiotherapy team – but I like that this is being more ‘proactive’ and not waiting for us to raise issues/concerns”
- “Such a good idea, should have been done years ago – you can pick up problems we don’t notice before they get too bad”
- “A brilliant idea”
- “We know the physiotherapy recommendations are important, but this helps us ask any questions or clarify any concerns without having to call the physiotherapist out specifically”
- Feedback from a 48 hour panel following a death of a service user highlighted the excellent work and practice by the physiotherapy team and all members of the panel were supportive of the annual review project.

## Challenges:

- The increase in workload in year 1 had been predicted, but still impacted on the service as referrals were also entering the service – effectively placed an additional 20 cases to our caseload in 2019.
- Getting feedback about the project from families and support staff was a challenge. Questionnaires were attempted, but not completed. A telephone follow-up was completed with many, however we recognise that the feedback may be biased towards the physiotherapy team as families/support staff may not wish to be seen as being ‘negative’.
- Getting feedback from GPs has been difficult. The aim was to align the physiotherapy review with the GP annual health check to ensure they had appropriate information 1 month prior to the annual health check – this was not deemed possible.
- Covid-19 meant a delay in completing assessments in 2020 with many families refusing assessment due to shielding – telephone contact was maintained and advice was given to these families in line with the assessment that had been completed the previous year. Specifically, for those whose activities had stopped such as hydrotherapy, rebound therapy and accessible gyms.
- The Southampton Physiotherapists have been in the team for many years so have good knowledge of the service users with PMLD. Challenges will be faced by others who may not have the relevant information to start identifying those who meet the PMLD criteria this may make starting the project more challenging

## Future plans to embed this initiative:

Although still in relative infancy, the number of physiotherapy referrals into the service from the annual reviews is reducing, showing that whilst the caseload increased for 1 year, the subsequent years have led to reduction in workload. Postural and health care needs are being met in a timely way, ensuring proactive intervention to those who are most vulnerable to undetected health

changes in our society. Equipment and treatment have been provided to many service users that has helped improve their quality of life, whilst minimising long-term care cost to the NHS.

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## The Get Going Group: dramatherapy for people with learning disabilities and mental ill health

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### Description

The Get Going Groups were developed following the Department of Health's national bed closures in 2015, with the intention of reducing institutionalised care and improve community provision. Patients on specialised Assessment and Treatment Units, designed for people with learning disabilities are first introduced to the Get Going groups when preparing for their discharge and then supported to attend post-discharge. The aim of using this process was to allow people's care to be monitored in the early stages of moving back to communities and to highlight concerns about their transition in the early stages. We know that people with learning disabilities and mental ill health find it difficult to integrate into the community (Mental Health Foundation, 2021) particularly after psychiatric admissions. These groups provide facilitated spaces to meet similar people who understand what they have experienced. This process is important in reducing isolation and loneliness once people leave hospital, as loneliness can be a significant driver of poor wellbeing among people with disabilities (Emerson et al, 2021).

The dramatherapy groups with the use of storytelling and drama methods such as role play provide people a space to meet new people. Dramatherapy is a psychological therapy that offers people with limited cognitive ability a way to communicate and express themselves when written or verbal communication is challenging. It is particularly suited to people where language acquisition and cognition is impaired, as it offers alternative ways of engaging (Beail, 2016). The Get Going groups allow people with learning disabilities an opportunity to communicate and engage with their peers, share their experiences and build friendships outside of hospital.

### Context

Approximately 1.4 million adults in the UK have a learning disability defined as a significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood (Mental Health Foundation, 2021). Approximately 40% of people with learning disabilities experience psychological distress and mental illness, which is more than double the rate of the general population (Bourne et al, 2020). Co-morbid health conditions and challenging behaviour can mask mental health problems and complicate treatment, which has meant this population have a

history of institutionalisation and unnecessary hospital admissions (Mental Health Foundation, 2019).

In 2011, the 'Winterbourne View Scandal' revealed people in a private inpatient unit were experiencing abuse from staff (Delamothe, 2013). The subsequent review highlighted the lack of progress in services and the government made a commitment to transform care and build up community capacity by March 2019; which included a national bed closure of 35% to 50% of in-patient beds with the aim that people should be moved to local communities with individualised packages of care. Eight years on the BBC's Panorama again exposed abuse and mistreatment of adults with learning disabilities and Autism at another privately-run NHS funded unit, Whorlton Hall; with video footage revealing staff intimidating and mocking patients, unnecessary restraining of patients and 'psychological torture'. There was a recognition that community provision was deficient, in terms of both quality and access there was a fundamental need for changes in provision of care. More recently the Covid 19 pandemic has once again highlighted inequalities in health care for this population.

Historically people with learning disabilities have not received much in terms of psychological treatment (Beail, 2016). Recent Government policies were set to improve services by prioritising research into the prevention of mental illness and core policies stating the importance of people with a learning disability accessing all forms of psychological treatment. The National Institute for Health and Care Excellence's (NICE, 2016) guidelines for psychological interventions for people with a learning disability and mental illness suggests when delivering psychological interventions, treatment should be tailored to their preferences, understanding, strengths and needs. Unfortunately, current mainstream services are not always appropriate or equipped; with traditional talking therapies difficult to engage with, even after adaptations (Bourne et al, 2020).

Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) developed two dramatherapy groups as a proactive approach to provide support to people with a learning disability after a hospital admission. People are first introduced to the groups, when preparing for their discharge and then supported to attend once they move to local communities. This approach allows their care to be monitored in the early stages of leaving hospital and any concerns highlighted about their transition.

The Get Going Groups have been running for five years, they are part of a Trust's discharge pathway from an Assessment and Treatment Unit (ATU). 'A Shinning a light' award was awarded to the group by the Trust for its mutual support approach.

## Method

Adults with a learning disability diagnosis and a mental health condition were engaged with this service.

Questionnaires were delivered at the start of treatment and repeated after the intervention (The Rosenberg Self Esteem Scale, The CORE LD, The Glasgow Anxiety Scale and The Glasgow Depression Scale).

The dramatherapy groups were delivered over twelve-weeks with sessions lasting 90 minutes. The community dramatherapy group is a manualised complex intervention with a large component following a mutual and peer support model. Mutual support is a model of peer support by and for people with learning disabilities with involvement of non-disabled people as allies. Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility and

mutual agreement of what is helpful. At the group the expectations include support staff forming part of the group, which brings a new dynamic and understanding between participant and care staff. This mutual support model offers a space for positive relationships to be built, which extend out into further community activities.

The session structure was familiar each week, to help with feelings of uncertainty: all sessions included a welcome, familiarised warm up game, story making and an ending with reflections. The group content and structure were based upon story development using 'the six-part story' method (Hackett & Bourne, 2014) which has component parts of a story: a character, a place or land, a goal, an obstacle, with some help to overcome the obstacle. This approach generates stories about a situation where a character or characters face a challenge and then requires some support. These stories form the basis for discussions at the groups as people are invited to debate how characters experienced help and what the nature of the help was (Hackett & Bourne, 2014). The stories offered insight into a person's difficulties so that constructive dialogues could be opened up and appropriate support identified. As the weeks progressed and stories developed, the story re-enactment stage was introduced which offered a brief role play, where people witnessing and discussed people's stories which helped enable peer and mutual support (Bourne et al, 2020).

## Outcomes

Evaluation shows the groups offer clinical benefits.

Findings from twenty people over a two-year period show:

- **Significant improvements** in self-esteem (mean = pre-intervention 21.35) following the intervention (mean = post-intervention 24.75), with a P value of  $p < 0.01$ .
- The CORE LD (covering well-being, problems, life functioning and risk to self and others) shows a **mean reduction** from 10.95 to 7.63.
- 'The Warwick-Edinburgh Emotional Wellbeing Scale' (WEMWBS) shows a **mean score increase** of 7.1 post group, indicating improvements in mental well-being.
- A **decrease in anxiety** (Glasgow Anxiety Scale - GAS) with a mean reduction of 4.8 post-group.
- A **mean decrease in depression** symptoms (Glasgow Depression scale -GDS) of 5.53 with a P value of  $p < 0.2$  indicating a significant statistical difference post-group.

Qualitative data (Bourne et al, 2020) from support staff who supported a person with a learning disability to attend the dramatherapy Get Going groups found the groups beneficial particularly the link with professionals.

P3..... "I think she's coming to a dip and I think coming to the Monday group when she's coming to a dip I've got somebody to talk to, so I will mention it to somebody".

P2..... "I've worked for the Trust for thirty years now and its very different world to when I started, and you see groups like this getting together and people working together with clients and you don't have an 'us' and 'them', everybody is looking after each other. I think its brilliant – it's all coming together."

## Key Points

Manual-based psychological treatments have significant impact on clinical research and practice, advantages including; efficacy, less reliance on intuitive clinical judgment, a greater ease in training and the supervising of therapists in specific clinical strategies and techniques. Theory- driven, manual-based treatments are a defining feature of evidence-based treatments due to their robust evaluation process, particularly in RCTs. In the future we plan to run a Randomised Controlled Trial (RCT) methodology to test the effectiveness of the manualised dramatherapy groups. Given the psychological clinical need for this population an RCT would result in a tested dramatherapy group-work manual for practice and an intervention identified for this population.

We have adapted the group during the Covid 19 pandemic and delivered it online. Pilot evidence suggests that the group was still able to support people during this difficult time. We hope to continue delivering groups remotely and gather further data to evidence the dramatherapy manualised group work for this population can continue to be accessible.

## Benefits & Learning

- People with a learning disability and mental illness find it difficult to integrate into the community after a psychiatric admission and need facilitated spaces to meet.
- Dramatherapy groups can be used to help support people back into the community after a long hospital stay.
- The Get Going groups allow a person's care to be monitored and concerns highlighted to the wider professional care team.
- Using a mutual support model can help people to feel valued and supported.
- Storytelling, play and role play can help people to share experiences when verbal communication is difficult.
- The Get Going Group manual can be adapted to be delivered online when people cannot get to a designated venue.

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