



Pyramid of Arts

High Rise Project 2015 – 2018

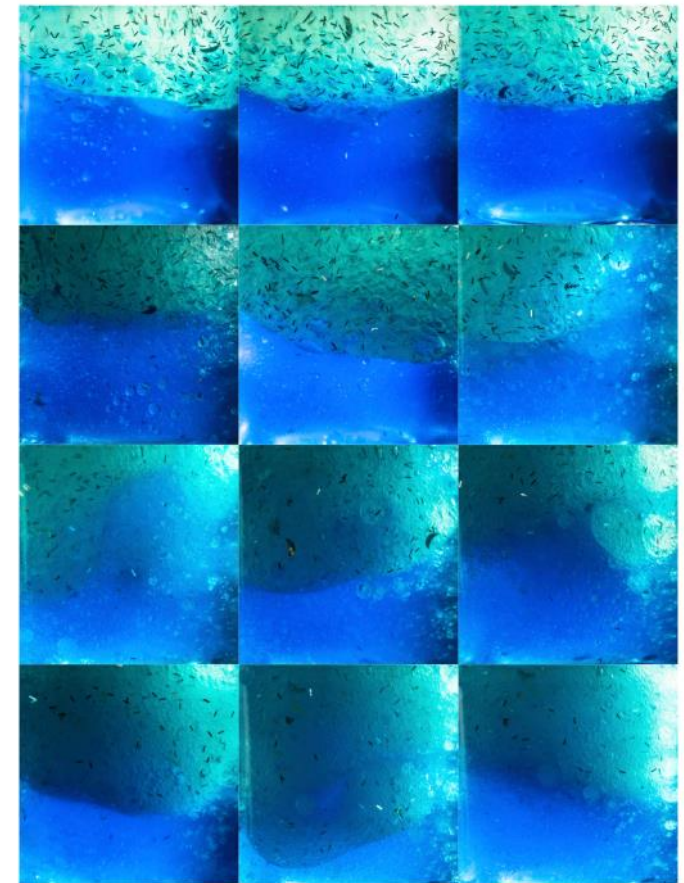
Evaluation Report

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High Rise Evaluation Report

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Sensory Jars by the Sensory Group

Director's Introduction

Pyramid of Arts' High Rise was an amazing three year programme of arts groups for people with profound and multiple learning disabilities. We ran several groups; two music groups, two movement groups, a visual art group and a general sensory group. We also ran weekly sessions in Parkside Lodge. Our members had severe learning disabilities and more often than not very severe associated physical impairments. They are amongst the people most at risk of exclusion from creative activity, and of social isolation. Our groups brought out their talents, skills and imagination to create beautiful sculptures, publications, music and musical theatre, films, parades and processions, workshops, and props for an opera performance. The work was performed and displayed in all of the most significant cultural venues and theatres

in the city, to large audiences across the three years. As well as improving physical activity, socialisation, mental health, confidence and resilience, the project allowed the amazing work of our members to be shared, with pride, professionalism and respect, with the general public in the city.

James Hill

Director, Pyramid of Arts



In memory of Lesley Sidwell, Caroline Paley, Andrew Spindley, and Stephen Waterhouse

Introduction

What the project was about ?

The High Rise project was funded by the National Lottery through the Big Lottery Fund. This unique programme provided creative opportunities for profoundly disabled (PD) people with complex learning and communication needs resulting from sensory differences, autism, and mental health illness. The project provided many opportunities for members to perform and create, and to have their work seen in public places. We had six groups that members were recruited to – Movement (2), Music (2), Sensory(1), Visual Arts (1), and a further group, Creative Wellbeing, that took place in a NHS acute inpatient service for adults who had learning disabilities and were in mental health crisis.

Original objectives

- Improvements to individual PD peoples' level of physical activity and motor skills, plus greater use and engagement of impaired senses.
- Improved mental health, confidence and resilience for PD participants, through increased social engagement and pride in public exhibition of work.
- Improved local care community/services through increased use of creative activities in care environments and staff confidence in skill-sharing.

Programme outputs

We predicted that once accomplished, these activities would produce the following evidence/service delivery: Social inclusion, wellbeing, involvement, production of work for public exhibition/ performance

Beneficiaries

The main beneficiaries of the project were adults with Profound and Multiple Learning Disabilities (PMLD). Other beneficiaries were artists, trainee artists, volunteers, support workers, and partner organisations. Indirect beneficiaries – family, general public, supported living residents and staff.

How we captured information

We captured information using the following methods:

Reporting in – written feedback and outcome measures; registers; group session diaries (scrap books); case studies; end of term evaluation meetings with artists and volunteers; database entry and collation; annual feedback from members and support workers; written and verbal anecdotal evidence; cultural events - photographs and/or video.



What we have achieved over the 3 year project

Snapshot		
Who and what	How many	Notes
Members	96	Across the three years
Volunteers	35	Three volunteers went on to become paid artists
Artists	20	Three trainee artists went on to lead artist and core worker roles
Sessions	608	
Exhibitions, performances, or events	32	See chapter 9 (page 26) for more details
Venues visited for trips	12	Thwaite Mills, Leeds Central Library, Carriage Works, Armley Mills, Leeds Discovery Centre, Skelton Grange, Seven Arts, Kirkstall Abbey, Leeds City Museum, Jack Rabbits Pottery, Yorkshire Dance and The Tetley

Year 1

We had 23 respondents to our annual feedback. Out of these 87% lived in supported living. Outside of Pyramid of Arts, 'eating out' and 'visiting friends or family' were the most popular activities. Only 1 person attended a full day service, and 65% attended a different group session, with 80% only attending 2 days or less. We asked the question, 'Has any of the following happened whilst attending Pyramid of Arts groups?' and the top three answers (asides regular attendance) were: *'Made new friends', 'increased active engagement', and 'increase in positive social engagement'.*

Impact

Group dynamics were set, and getting to know members was the artists' priority; in the first year we focussed on the members needs and how to approach the group sessions to include all these needs. We began establishing partnership links, working with external artists and venues. There was a heavy focus on recruitment and marketing, learning from the previous High Support project (2010-2013) we wanted to recruit members who were not known to us, and outside of NHS supported living. Nationally 65% of adults with PMLD live in private households¹, marketing included contacting other LD organisations in Leeds, private supported living organisations, adult social care, as well as attending events, meetings, and completing home visits.

Year 2

We had 23 respondents to our annual feedback. Out of these 96% lived in supported living. Outside of Pyramid of Arts (POA), 'eating out', 'visiting culture' and 'visiting friends or family' were the most popular activities, only 2 people attended a full day service, and 30% attended a different group session.

We asked two extra questions* for the question, 'Has any of the following happened whilst attending POA groups?' in this feedback. The top three answers were:

**'Felt important and included', 'increase in positive social engagement', and *'enjoyed the visits'*

We were pleased that the visits were well received, as we had organised many trips to museums, galleries and green spaces around Leeds throughout the year.

Impact

We had recruited more members through our focussed marketing efforts in the previous year, including creating a film for the under subscribed Movement and Music groups, this led to more privately run supported living organisations becoming involved with POA for the first time. We still needed to focus more on recruiting the hard to reach individuals who lived in private households with family. Further partnerships were formed, especially with Leeds Museums and Galleries (LMG), and following on from the success of 'The Golden Football' as an external performance, we arranged for more visits across the groups. We also worked at an external venue for a number of weeks with the Visual Arts group. We found

that familiarity with the other group members helped when we were in new environments, and completed risk assessments to include safe spaces where the members could go to if they became overwhelmed or upset at any time, however, we seldom used the safe spaces for these reasons. Support workers were inspired by new places to take people, with many not realising that they were as accessible as they were. This year regular attendance and group stability started to occur, which had a huge impact on the group members output. We found that the Sensory group was difficult to recruit to, and that a number of the members also displayed behaviours that challenged, which the artists had to respond to individually, so it was decided that the group would focus on 1:1 style interaction, within a group setting. Creative Wellbeing at Parkside Lodge was moved to 48 weeks due to the nature of the setting; as a locked ward hospital we could not predict how many people would be admitted at any one time, and it felt unjustified to break for the school holidays when there could be more admissions.

Year 3

Of the 46 people attending the groups 21% lived in private households, 47% supported living and 32% in NHS supported living. 'eating out', 'visiting cultural venues' and 'visiting friends or family', were the most popular activities. 64% of respondents to our annual feedback told us that they would like to see more drama, music and movement groups.

By far the most important thing to happen to the members was

that they *‘made new friends’, ‘that they felt included’,* and that attending *‘increased their active engagement’*.

We looked at what barriers there were to attend activities generally, and transport, staffing and cost were the main contributors as to why an individual could not attend.

Impact

From the continuing momentum of the previous year’s recruitment, word of mouth, and an updated website, the groups expanded and numbers filled the groups to capacity. We had started recruitment from across the sector, as there was more impetus in Leeds to use directories to find organisations. We attended the launch of Social Prescribing in Leeds, and updated our entry on the Leeds Directory database, which is used by the three local Social Prescribing programmes funded by the Leeds Clinical Commissioning Groups); we also met with the LD adult social care team on a number of occasions at ‘Meet the Provider’ events, as well as the introduction to involve social workers more with finding suitable activities for people with LD through the signposting organisation, Through the Maze. The stability remained in all groups throughout the year, with new members joining and finding the group dynamic to be welcoming and nurturing. The groups were involved in activities which took them out of the centres and working with partnerships such as LMG, this had a great impact on both the individual members and the public through the ‘normalisation principle²’ and by giving the members social role value that they many had not experienced before³.

What we couldn’t achieve

As discussed in chapter 10 (page 32) in greater detail, we created a method to capture and record the outcomes. However, we decided early on that we could not record an informed outcome about the improvement of members motor skills, and/or greater use and engagement of impaired senses, as the artists were not trained professionally as therapists. We did asked this question in our annual feedback, which was sent to each member’s support worker to fill in. We moved from a medical model of disability to a social model of disability when we answered the question of change in impairment, and the artists created their sessions to work with the individuals impairments, rather than trying to ‘fix’ them.

What we have learnt

We asked for written feedback from the members and their support workers, as well as having discussions with them when visiting sessions. From this feedback, and from changing our focus to a social model of disability, we worked with the members to ensure that we were involving people more and that they felt valued. What has stood out for some members is that having fun, and being with friends/peers is really important to them, as most of their other activities are health related (such as hydrotherapy). We looked at the ‘quality of life index’ as a tool to show that the members needs exist beyond medical care—having a value in society is incredibly important, and Pyramid’s High Rise has proven crucial in making this happen.



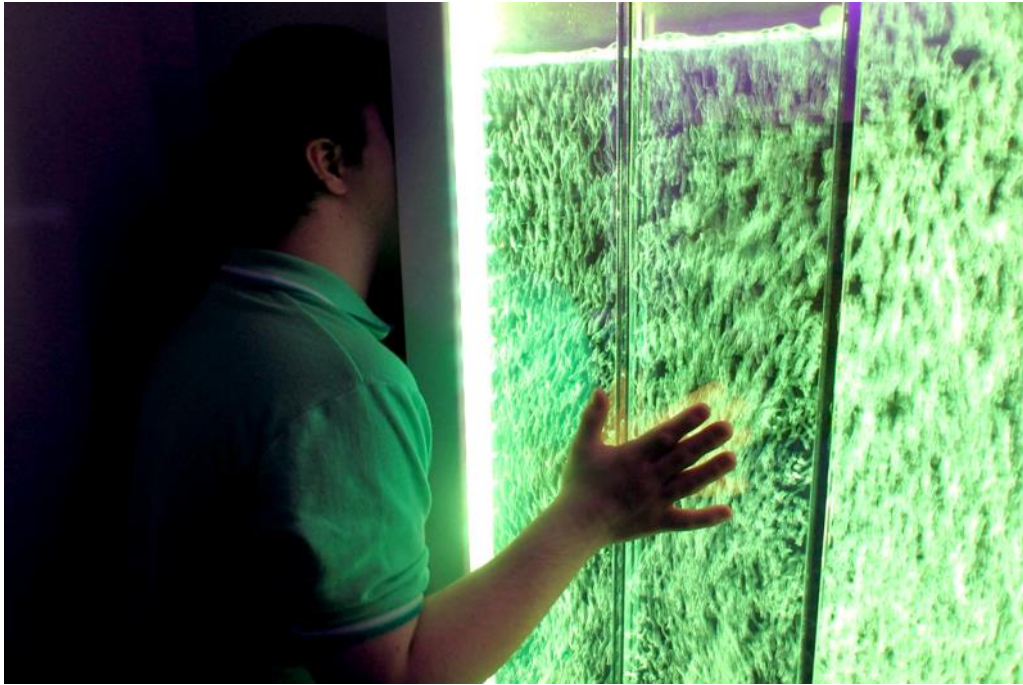
High Rise Sensory

High Rise Sensory was a multi-sensory experimental group. It provided a starting point for people who demonstrate very little engagement or response to the outside world, or who found larger groups difficult to navigate. It used imaginative, sensory stimuli

and simple structured activities and games to explore ways of unlocking communication through touch, sound, vision and movement. The group worked 1:1 with members, developing relationships and interactions.

Case Study

“D was a regular member of High Rise from October 2016. D attends a local day centre, and after attending a Pyramid of Arts session there, his support worker was keen to get him involved with High Rise. He joined the Sensory group and has really benefited from the small group numbers and intensive interaction he has received. We have learnt from his needs, and how he explores space. D really enjoyed playing the musical instruments we have purchased specifically for him – being thrown to the ground is part of their appeal, and he enjoyed participating in the rhythm sessions. D explored space through his auditory, tactile and proprioceptive senses, discovering how sound vibrations travel through different mediums. He became much more settled over time and was much more relaxed and cheerful in the sessions. He was encouraged to participate and regularly sat with the artists, after a period of self imposed isolation. He has enjoyed the use of the Sensory room at The Vinery.



High Rise Visual Arts

High Rise Visual Arts group offered practical art techniques for those who could demonstrate a developing capacity to handle tools and materials with minimal support. Participants worked on individual and large-scale works, which had the aim to improve

their communication, decision making skills, creative ability and fine motor skills.

To give the group routine, each session started with a cup of tea and finished with a story using Makaton and sensory props.

Case Study

“ H was a member of High Rise Visual Arts from May 2015. H grew in confidence since being in the group, as did her skills as an artist. She contributed to all projects and enjoyed the trips we took to other venues. H had a generally good level of wellbeing, and she interacted well with others, including artists and volunteers. She appeared happy and settled well into the group.

“ B was a member of High Rise Visual Arts from May 2015. He rarely missed a session and had settled into the group well; his support workers gave feedback that he gets excited on Wednesdays because it is Pyramid of Arts day. He had a generally consistent and high level of wellbeing, and he participated well with others, including artists and volunteers. He was a fun and happy member of the group. He bonded with a new member when they joined in Summer 2017, and formed a friendship over the following months.



High Rise Movement

High Rise Movement used storytelling, building on the story each week. Sequences were used to extend the range of participant's movements and improve flexibility and stamina. The use of simple props, such as feathers, elastic rings, massage balls and scarves; working in pairs and small groups; encouraged regular eye contact and communication. Participants explored limitations of movement, undertaking activities to extend both their fine and gross motor skills

and improve decision making and confidence.

Each session the group opened with a 'Hello' song, welcoming the members into the space, and a check in to give the members an opportunity to say how they are and what they have been doing, and to ascertain the temperament of the group members. They finished with a cool down and a cup of tea and biscuit, which gave the members an opportunity to socialise and chat.

Case Studies

“R was a member of High Rise Movement from May 2015. She enjoyed having the freedom to explore the space without any restrictions. We enjoyed her cheekiness and the interaction she had with other members. She formed a close bond with another member, after spending the first year exploring the space alone. The artists communicated with her well using a reciprocal response. Often when she had arrived in a low mood or agitated the space had given her the freedom to improve her mood and she has left the group appearing much happier. The familiarity of the group and the welcome song brings her into the group to participate with others.

“ S was a regular member of High Rise Movement from November 2016. Attending the group gave S positive attention. He told us that he was “happy” and excited to be in the group, and looked forward to coming. He offered ideas towards performance, was keen to dress up, and he enjoyed posing for photos. He was generally happy and up for almost anything, he would dance and move around the space. He watched intently and was able to copy movements and actions, often volunteering to help. The artists learnt from him, to not over stimulate him as he became quite overwhelmed, and they found solutions by being more aware of his needs, so he could continue to participate.

“ J was a regular member of both the High Rise Movement and Music group from January 2017. In both groups she enjoyed exploring the space; and as she became familiar with the environment she was in and recognised the group members, she became more relaxed and at ease. J’s support workers also noticed that she was happier in the sessions, informing us how much the groups had improved her quality of life. J formed a close bond with another member in the Movement group, and they have been known to comfortably hold hands. She also interacted with other members, moving around the group to say hello individually. Her trust grew with the artists and volunteers, for example, putting her head on the musician’s shoulder so she can listen to his guitar or taking the movement artist’s arm to lead her around the room.





High Rise Music

High Rise Music explored the creation of sound, including musical improvisation, sound layering using vocal and instrumental sounds and performance. Participants engaged in sound making using various tools to encourage communication, confidence and fine motor skills. The groups created their own unique musicals using the element of chance, such as rolling picture dice to develop the story line, as well as asking group members and their support staff questions as to what event they would like to occur next in the

story. The music and songs were inspired by the instrumental playing, vocalisations and movements of the group members. Each session began with a 'Welcome' song and a cup of tea as the members arrived. The session closed with a 'Goodbye' song as the members were leaving. Both songs were personalised to include the members' names, so that they were aware they were being acknowledged.

The group created 7 unique musicals over the project's three years.

Case Studies



A was a regular member of High Rise Music group from May 2015. A is visually impaired. He joined the group as a sleepy participant, however overtime he became much more energised. With support he enjoyed moving around the space to the music, singing, and always with big smiles. He worked hard with lots of commitment to the group effort, contributing words and ideas. He loved dressing up and being centre stage. He has a great memory and can perform on different instruments for different parts. He really enjoyed the trip to Leeds Discovery Centre, where he was able to handle museum objects in the big store.

“ W was a regular member of High Rise Music group from June 2016. She loved dressing up and really brought a theatrical edge to her performances. She tried really hard, exploring all the instruments, but loved using the shakers. She used her iPad to communicate words, which slotted into the songs perfectly. W was energetic, enthusiastic, cheerful, cheeky, and was a delight to have in the group. Sometimes she liked to just watch and listen, pushing herself into the middle of the group, and simply being with the others, she interacts well with everyone. W really enjoyed working with the guest singer from Leeds Lieder.

“ R was a regular member of High Rise Music group from September 2015. She would spend the sessions dancing and exploring the space, she would stop to move to the sound of the music in a purposeful style, enjoying the freedom she had to move around. Having the space to move freely and take risks, R became less agitated. She explored the instruments, the sounds and vibrations they make through touch and with her mouth. She would hum when she was enjoying the sessions, and started vocalising along with the music. She interacted well with the artists, she played the keyboard with Toni, or strummed the guitar with Seb. She became aware of what was happening in the group, stopping to process before continuing her movements or playing instruments, there were lots of intentional and purposeful decisions being made.





Creative Wellbeing at Parkside Lodge

Creative Wellbeing was created to work with adults with LD who are in mental health crisis. We approached Parkside Lodge, an acute inpatient service, which is for those service users whose complex health needs are such that they cannot be met in community settings. The artist team had a tool kit to provide a variety of art forms to work on individual needs. As service users entered the unit in mental health crisis, the artists had to develop

ways to work with an ever changing membership and group dynamic. This involved working 1:1 in different lounges, providing work to do in the safety of the patient's room, and in a regular group setting. Creative Wellbeing produced collaborative pieces that could be constructed from individual work, or worked on together as a team.

Case Study

“M was very anxious and had several occasions of crisis where they were not able to attend the group. However, the activity was clearly having a positive effect on the member as he began telling staff members about that he was looking forward to the Thursday Pyramid group. His confidence had grown throughout, with patience from the artists, who encouraged but not put any pressure on him to participate or to join in with the group work at the table. After several weeks the member was initiating social interaction when this had not happened before and is finally showing pride in his own work.



Events, performances and exhibitions

You can see in the table below, as well as in the pictures throughout this publication, the extent of the public-facing elements of the programme. Our initial estimate was that we would do 12 performances and exhibitions over the three years however we very much underestimated how confident and prolific our artists would be. In fact High Rise were involved in 32 events, performances and exhibitions. The work on display varied from anarchic, funny and colourful musicals performed in the city's best theatres and music venues, to 'Pyramid View On...' events, where

our members shared their responses to temporary exhibitions in visual arts venues such as the Tetley Centre for Contemporary Art. Work was not just exhibited at events organised by Pyramid but was selected to be shown in externally organised exhibitions such as Shoddy, which was covered by both national and local press. They performed with a professional opera singer of international repute, and performed live in such impressive venues as Kirkstall Abbey.

Year 1				
Group	What	Where	When	Attendance
Sensory and Visual Arts	Both groups created pieces displayed in the <i>Shoddy</i> exhibition. The exhibition was reviewed in the national and local press.	Live Arts Bistro	6 th -16 th April 2016	434
Music	The group developed new ways to create storylines, lyrics and sounds, coming up with <i>The Golden Football</i> .	Carriageworks	1 st April 2016	45
Movement	The group created their own abridged version of the <i>Wizard of Oz</i> . They performed to a small audience of friends and families.	Cardigan Centre	28 th April 2016	10

Year 2				
Group	What	Where	When	Attendance
Sensory	The group had their textile creation shown at a second event for <i>Shoddy</i> .	Batley Art Gallery	28 th May-11 th June 2016.	240
	High Rise had work shown as part of the biennial <i>BEYOND learning disability and the arts in Leeds</i> festival:			
Movement and Music	Films were shown at a showcase exhibition for BEYOND in Room 700.	Leeds Central Library	10 th -24 th June 2016	1150
Movement and Music	The films were also shown at the BEYOND Festival Day.	West Yorkshire Playhouse	18 th June 2016	500
All	Photographs that had been taken throughout the first year of the project were displayed at a showcase exhibition for BEYOND.	Left Bank	10 th -24 th June 2016	200
Movement and Music	Members of Movement and Music group inspired a workshop held during the <i>No Quiet Place</i> exhibition.	The Tetley	25 th June 2016	94
Music	The group performed songs from their musical <i>Elements</i> in the open surrounds of the Church at Kirkstall Abbey.	Kirkstall Abbey	1 st July 2016	30
Music	The artists held a workshop during Horsforth Walk of Art, where photographs of the projects were also on display.	Woodside Methodist Church	2 nd July 2016	30
Movement	The group created work which was shown as photographs during <i>Kirkstall Art Trail</i> . The trail was reviewed in local press.	Kirkstall Abbey	16 th -17 th July 2016	507

Continued over page ➡

Group	What	Where	When	Attendance
Visual Arts	The group created a clay mobile inspired by their time spent at the environment centre. It is now on permanent display there.	Skelton Grange	Summer 2016	Permanent display
Visual Arts and Sensory	The groups were included in a publication about the <i>Shoddy</i> exhibitions, which was launched alongside previous exhibits.	Inkwell Arts	12 th -23 rd August 2016	Publication only
Creative Wellbeing	The group created a collaborative piece which was part of the <i>Art of Recovery</i> exhibition. They won a 3rd Prize for Judge's Choice.	Corn Exchange	7 th October 2016	Not known
Music	The group performed an original musical called the <i>Viking Quest</i> , as part of the 'Winter Stories' showcase.	Leeds Industrial Museum	21 st January 2017	80
Movement	The group created an immersive sensory experience called <i>The Owl and the Polar Bear</i> , as part of the 'Winter Stories' showcase	Leeds Industrial Museum	21 st January 2017	20
Visual Arts	Illustrative scenes of <i>Peter and the Wolf</i> were displayed and the story read aloud with signing, as part of 'Winter Stories'.	Leeds Industrial Museum	21 st January 2017	15
Sensory	The group created a tactile wall hanging, in the Spring term of Year 2. It is now on permanent display at Leeds Mencap.	The Vinery	Spring 2017	Permanent display
Movement	The group created an immersive in response to the Dora Garcia performance, <i>These Books Are Alive; They Spoke to Me!</i>	The Tetley	30 th March 2017	20
Music	The group collaborated with Leeds Lieder and created <i>Step into Spring</i> . It was part of the Leeds Lieder Festival programme.	Yorkshire Dance	21 st April 2017	40

Year 3				
Group	What	Where	When	Attendance
Sensory	The group created a 2 nd tactile wall hanging, in the Summer term of Year 3. It is now on permanent display at Leeds Mencap.	The Vinery	Summer 2017	Permanent display
Music	The group created an original musical called <i>A Seaside Musical</i> .	Woodside Methodist Church	21 st July 2017	15
Visual Arts	The group's clay mobiles were part of a show, <i>Swarm, at the environment centre. The exhibition was reviewed in the local</i>	Skelton Grange	September 2017	Not known
Music	The group responded to the <i>50 Years of Leeds West Indian Carnival Exhibition</i> , playing a small number of songs.	The Tetley	20 th October 2017	8
Movement	The group responded to the <i>50 Years of Leeds West Indian Carnival Exhibition</i> , and lead a <i>Carnival Parade around the venue</i> .	The Tetley	19 th October 2017	27
Music	The group created an original musical called <i>Stinton the Musical</i> .	Seven Arts	8 th December 2017	38
Music	They performed <i>The Viking Musical</i> as their swan song to this three year project.	Seven Arts	16 th February 2018	45
Creative Wellbeing	The group at Parkside Lodge displayed a collaborative textile wall hanging as part of the Pyramid of Arts Group Exhibition.	Swarthmore Education Centre	26 th February-26 th March 2018	800
	The project held a Celebration Day to mark the end and success of the High Rise Project.	Leeds Industrial Museum	28 th April 2018	72

Database and Outcome Measures

The project captured information and statistics in several ways, and we strived to collate information that is consistent and useful to both the members and Pyramid of Arts as an organisation.

In the first year of the project we looked at ways in which to improve data capture from our core workers and have a standardised system across all our groups, including those outside of the High Rise project. We wanted to be able to see clearly any movement in terms of a member's development within in the groups, and to see if there were any positive changes within their activity, participation, and wellbeing. Previous projects offered convoluted ways to capture this data, which required core workers to fill out pages of paperwork per member, each session. For both core workers and project coordinators, this would be a time consuming method to analyse and capture the data required to evaluate the project. In response to this we developed a method that would use a numbered system with descriptors, that related to the members time in that session. These outcome measures are a combination of existing measures:

- Therapy Outcome Measures (TOMS used by the NHS)
- The Leuven Wellbeing and Involvement Scales
- And the Social Model of Disability (as described by Scope)

The measures follow the basic principles as follows - Impairment, Activity, Participation & Wellbeing (IAWP)

It was important for all our staff and freelancers to understand that it is not scoring an individual, or placing members on a hierarchy. The measures will show that we will have low days, and periods when we don't want to take part, and this is all part of someone's journey at Pyramid of Arts. However, the measures can be used to see at a glance if a member is not enjoying, participating or achieving anything during the project – which is something that should be addressed. We use the outcome measures to track an individual's progress, and to offer an overview of how the projects are working with an individual's needs. The outcome measures have descriptors, which offer a guide to relate to what is recorded.

This method also evidences social return on investment that our funders expect from us. Records of individual members can inform their care plans with our partners.

The database was developed and created alongside the outcome measures, over the first year of the project. It holds information for all our members, staff, artists and volunteers; projects; venues; events; and groups.

Within groups we can enter the reporting in that the core workers return to us each week. We can quickly pull up reports on each

individual which will concisely show their progress, their time in the groups, and the ability to evaluate at a glance against the aims of the project. This report is also valuable for creating individual case studies.

Full descriptors

Impairment – in line with the 'social model of disability' refers to the degree of success by which the session has been designed and run in order that the member can participate despite their impairments.

0 A member's impairments mean that they are unable to take part in the session at all

1 Some occasional response and participation from the member

2 Increased response and participation from the member

3 An understanding of the member's impairments has allowed the workers to design processes or tools which allow the member to get more involved in the group activity

4 Use of tools and processes which support the member to get involved in most (80%) of activity in the session

5 While a member's impairments remain, the session has been run and designed in such a way that the impairment does not affect the member's involvement at all. They can fully take part

Activity – refers to the difficulties an individual may have in the performance of activities.

0 Totally dependent/ unable to function

1 Assists/ co-operates but burden of task/ achievement falls on professional carer

2 Can undertake some part of a task but needs a high level of support to complete

3 Can undertake task/ function in familiar situation but required some verbal/ physical assistance

4 Requires some minor assistance occasionally/ or extra time to complete task

5 Independent/ able to function

Participation – refers to being intensely engaged in activities, making own choices, and being integrated within the group.

0 None – No autonomy, is not involved, made no own choices

1 Extremely Low – Their activity is simple, repetitive and passive. They seem absent and display no energy. They may stare into space or look around to see what others are doing. Limited integration, made very limited choices.

2 Low – Frequently interrupted activity. Will engage in the activity some of the time they are observed, but there will be times when they may stare into space or

The measures with full descriptors, as used by the core workers and artists for their feedback, are outlined below. There are examples of how these measures are explained to new workers during their core worker training on the next page.

be distracted by what is going on around. Some integration, made some own choices

3 Moderate – Mainly continuous activity. They are busy with the activity, but at a fairly routine level and there are a few signs of real involvement. They make some progress with what they are doing, but don't show much energy and concentration, and can be easily distracted. Some integration, made own choices.

4 High – Continuous activity with intense moments. They have intense moments and at all times they seem involved. They are not easily distracted. Integrated, made own choices.

5 Extremely high – Shows continuous and intense activity revealing the greatest involvement. They are concentrated, creative, energetic, and persistent throughout nearly all the observed period. Integrated, made all own choices.

Wellbeing – refers to feeling at ease, being spontaneous and free of emotional tensions, self-confidence and a good degree of self-esteem and resilience.

0 None - High and constant levels of distress/ upset/ concern/ frustration/ anger/ distress/ embarrassment/ withdrawal/ or apathy, unable to express or control emotions appropriately. Behaves aggressively, hurting themselves or others.

1 Extremely Low – Shows signs of discomfort such as crying, or screaming. May look dejected, sad, frightened or angry. Does not respond to the environment. Avoids contact and is withdrawn. May behave aggressively, hurting themselves or others.

2 Low – the posture, facial expressions and actions indicate that they do not feel at ease. However the signals are less explicit than Level 1, or the sense of discomfort is not expressed the whole time.

3 Moderate – Has a neutral posture. Facial expression and posture show little or no emotion. There are no signs indicating sadness or pleasure, comfort or discomfort.

4 High – Shows obvious signs of satisfaction (as shown under level 5). However these signals are not constantly present with the same intensity. Occasional emotional support/encouragement needed.

5 Extremely High – Looks happy and cheerful, smiles, 'cries' out with pleasure. May be lively and full of energy, actions can be spontaneous and expressive. Appears relaxed and does not show any signs of stress or tension. They are open to the environment, expresses self-confidence and self-assurance.

Understanding the Pyramid of Arts Outcome Measures

We use the outcome measures to track an individual's progress, to report back to our funding providers, and to offer an overview of how the projects are working with an individual's needs.

How to complete the measures

Physical

The first two measures look at how well you have designed for each individual in the group. This is about how you work with individuals to include them in the group activity, and learning with each other (there will be some information about the individual before you begin the project, such as a 'One Page Profile'). This is the physicality of being able to do the group work.

Impairment

Impairment looks at how well you have designed the sessions for the members. It can help identify individual needs and what adaptations you may need to take to create a session that includes them. Examples could be as simple as giving a member a pair of gloves because they do not like touching clay.

Activity

Activity looks at how much difficulty the individual has in performing the task. There will be cases when a person will always require support, this does not mean they are 'scoring low', it is showing an honest representation of ability. However, as the artist and core worker, you can design sessions that become familiar and autonomy can develop. This may be something that takes a long time, and an individual's level of activity may increase, but be mindful that every individual has their own pace of learning and their own comprehension of what you are doing.

Cognitive

The next two look at the way in which a member cognitively relates to the group activity.

Participation

Participation refers to being intensely engaged in activities, making own choices, and being integrated within the group. A member may not wish to join in the activity – which is making own choice, and still be present within the group, watching, listening, socialising. Participation is about being present in the group.

Here is an example:

Darren has decided he does not want to play the drum today, he refuses to take the beater, and gives it back to you. He is listening and alert, and makes happy noises at appropriate times to the music. He watches you intently when you are playing the drum, nodding his head in time to the music. He smiles at other members of the group, and it is clear he is enjoying being in the group environment. Although his participation is more passive than usual, he is still involved with the group and is still engaged with the music, he has made a choice to listen and enjoy, rather than be an active member.

In this example we would measure participation as a 4 = 'Continuous activity with intense moments. They have intense moments and at all times they seem involved. They are not easily distracted. Integrated, made own choices.'

The wording for Activity in this example does not fit with the participation score, so use own discretion and mark as normal activity. The importance here is the choice and integration.

Wellbeing

The easiest way to do this is to ask the member during the group activity. An individual generally knows their own wellbeing. If asking a person, who is nonverbal, or their communication and comprehension of, 'how are you?' is limited, it is down to your observation, or perhaps asking the support worker, who knows them best.

Another way to gauge wellbeing is to do a check in at the beginning of the session, if Belinda is said to be cranky at the beginning, but by the end of the session she was smiling and happy, we can tell that she enjoys the session and being with the group.

Look at the wording on the descriptors and ask yourself if this would correspond to the individual. It is a very subjective, so don't get too caught up in analysis, we are not psychologists. Wellbeing, and asking how our members are, can help with safeguarding too.



Project Conclusion

1. Improvements to individual PD peoples level of physical activity and motor skills, plus greater use and engagement of impaired senses.

Indicators

- Members show increased active engagement in specific creative activity over the course of their attendance at groups – Overall, analysing the measures on the database, the majority of the members became more engaged.
- Members with impairments to their senses show increased sensory responses to creative and social activities within the group – we had one member who was declared deaf by her support workers, who showed signs of awareness and response to auditory stimuli. Although the core worker's did not measure this outcome in detail during the session, annual feedback showed 9 members increased their sensory responses.
- Members show increased physical movements over the course of their attendance to groups – Again we did not measure this outcome in detail during the session. Annual feedback showed 9 members increased their physical movements.

2. Improved Mental Health, confidence and resilience for PD participants, through increased social engagement and pride in public exhibition of work.

Indicators

- PD people attending and returning to our groups regularly for each a year – 96 people over the 3 years attended groups. Reasons for leaving – transport, staffing, felt it wasn't right for the individual. 4 members sadly passed away. At the end of the project we had 49 regular members, 2 of whom were attending 2 different groups.
- Members show decreased stress or increased positive social engagement over the course of their attendance at groups – Overall we saw improvements to wellbeing across all members, as recorded on the database. Improvements to self-worth and feeling valued within the groups also grew over the three year period and was also recorded in the annual feedback.
- Work displayed in at least 12 high profile public cultural events, with PD members present at those events with at least 3 previews/reviews of events in local press – High Rise was involved in 32 exhibitions, performances or events over the three year period. High Rise was mentioned across local social media, and in some press.

3. Improved local care community/services through increased use of creative activities in care environments and staff confidence in skill-sharing.

Indicators

- Artists and volunteers working in our groups obtain practical experience of using creative activity in work with PD people – Initially experienced core workers and lead artists mentored the trainee artists and assisted them in completing their trainee objectives. They also mentored volunteers who showed interest in furthering their development to complete this training. This experience moved 6 of our trainees and volunteers into paid roles or core worker/ artist roles.
- Artists and volunteers' completion of Foundation and Making it Happen training. – Artists and Volunteers were invited to attend our in house training:
Foundation training equips people with a greater understanding of some of the challenges facing people with learning disabilities and enables them to provide appropriate support.
Explorations (formerly Making it Happen) looks at practical planning and facilitation issues when delivering projects which involve people with learning disabilities. Participants also gain awareness and skills in project planning, health and safety and documenting and evaluating projects.

Core worker training, the artists and volunteers attended this additional course, which helped develop their knowledge and looked at the specifics of managing groups needs, as well as policies and procedures. In addition to this training, the artists also attended Intensive Interaction Awareness, Safeguarding, and Emergency First Aid at Work.

Course name	Foundation training	Explorations	Core worker training
Number	11	5	7

- Care workers more likely to use creative activities in their work environments as a result of attendance at Creative Approaches to Everyday Living (CAEL) training – **CAEL** was a short course developed for support workers and carers to promote creative activity. We delivered the training to 8 members of staff at Aspire CBS, the feedback we received was mostly positive and showed how creative arts can be used with limited resources; that things can be silly and fun, playing is for everyone, even adults; to be confident with the work without having to justify it; that the process is as important as the end product, which you don't always need. We also included support workers in activities within the group sessions – encouraging them to participate and contribute as a member of the group. Support workers have mostly responded well to tasks.

Impact and change

Our evaluation has shown that working with PMLD is not straightforward, and a lot of positive and intensive interaction between members and POA workers is required. As the team have had Intensive Interaction Awareness training, this has helped with the way in which they engage with our members.

Communication is largely non-verbal, so a deep understanding of what the members' needs and choices are is required. Working closely with PMLD individuals, exploring and identifying different methods to engage and achieve a response is imperative to include all members at all levels of ability.

Positive outcomes from our work with PMLD has shown that it can improve confidence, give members a space to explore and safely take more risks, and is an activity that they look forward to, that gives them a sense of achievement and purpose. Members have been able to make and retain meaningful relationships with their peers, which has a huge impact on their emotional wellbeing.

Our groups embrace public engagement, such as performing to an open audience, interacting with other organisations, visiting museums, galleries, and green spaces. It is important to be public facing for two reasons: Firstly, people with PMLD deserve to access the same provisions as the rest of the public and secondly, giving people with PMLD the opportunity to access public space, will enhance views of the person, and remove negative connotations around disability. We endeavoured to create projects

that happened in shared public spaces and engaged everyone nearby. Our work with PMLD adds value to the organisations that we work with.

Quotes from members, support workers, and family

“*It has been a positive experience to see them progress from being quite stressed by attending the group at first, to really enjoying it and having positive social interactions.*”

“They seem happier when they have been able to attend, see their friends, and have fun at the sessions. Social interaction with peers was previously very limited and having this has improved their quality of life”

“[attending POA] has widened my friendship group. I have visited new places – I had never been to the Tetley, Seven Arts, or Armley Mills before. Every group I attend is important to me.”

“Enjoy seeing A interacting, and seeing how highly staff at POA regard her”

“Opened our eyes to new ways of creative support – all positive and inclusive”

“[Attending sessions at Pyramid of Arts has given me a] better relationship with [my client]. Enjoyable to see her in a different environment socialising with others”



Legacy

Continuing groups

Due to the demand and need for groups such as High Rise in Leeds, we introduced membership fees to open the Movement and Music groups up to existing members on a continuing basis. Of the original members of the High Rise project, 50% have taken up paid membership.

During home visits to recruit new members, we were told that there is not any other activity like ours which are specifically aimed at adults with PMLD, and that their calendars are empty.

Projects and presence in the community

Chris Sharp, Assistant Community Curator at Leeds Industrial Museum at Armley Mills and Thwaite Mills Watermill, said, “the scope of the work Pyramid of Arts does with their members with profound and multiple learning disabilities is very inspiring. Over the past 18 months I have worked with Pyramid on quite a few occasions at Leeds Industrial Museum, Thwaite Mills, and Leeds City Museum – and supported a varied and creative programme that has obvious benefits so plain to see to the people they work with.

“In January 2017 Pyramid took over Leeds Industrial Museum on a Saturday afternoon to stage performances, workshops and displays as part of their ‘Winter Stories’ project. This added great

value for other visitors to the museum that day, as they were able to enjoy and take part in the activities prepared and performed in conjunction with people with profound learning disabilities – which I hope also helps break down perceived barriers between regular museum visitors and groups such as the [PMLD Pyramid] groups, and challenges the expectations and preconceptions people may have concerning individuals with learning disabilities. I have seen the growth in confidence, and enjoyment, that Pyramid bring to their members through creative outlets.” (October 2017.)

Database and outcome measures

The Database and outcome measures are now used across all groups. The reports have assisted with funding bids, as well as keeping track of members’ activity, and reporting to other funders when necessary.

Research

Working on this project has required a great deal of research into PMLD, looking at communication, interaction, opportunities and activities aimed specifically at this demographic. Moving to a social model of disability opened up the manner in which we could make the project more inclusive. Researching to find what leisure

activities are already available and accessible for adults with PMLD in Leeds and across the UK, showed that there is a real need for groups like High Rise to exist, in Leeds and nationally. Adults with PMLD have some of the most restrictive lifestyles. “Not only are they more likely to have smaller networks, but the complex interpersonal skills required to initiate and maintain friendships will make it more difficult to make the most of available opportunities for developing their relationships” and “research still [indicates] that much is to be done before people with PMLD can be said to be participating in their local communities in any meaningful way.”⁴ Research looked at ways we could work with individuals who have profound communication impairments, and how we can involve them more with choice and decision making. The project coordinator attended training that looks at Social Impact reporting and how to apply this to High Rise, working with a demographic that is under researched on a social level.

Influencing future projects

‘Supporting people with profound and multiple learning disabilities: The Core and Essential Service Standards’ are designed to improve the lives and life experiences of people with profound and multiple learning disabilities.

Following their standards we focussed on:

“Inclusion in activity is participation at a meaningful level to the person involved, not simply tokenistic by simply being present, for

example, through the use of Active Support”⁵

“People are “visible” and actively involved in their communities and the activities they do; they are not passive recipients.”⁵

Our primary and secondary research continues to show that adults with PMLD are not in control of their lives, and involvement is something that we are keen to make a priority; giving people with PMLD self-determination over their decisions and choices.

Looking at a specific area of Leeds, we are writing a proposal centring on community cohesion and reducing social isolation. This research feeds into how the project proposal has developed, and how we hope to continue our work with PMLD in this respect.

Assistant artists

Following the introduction of trainee artists to the High Rise groups, they have been able to develop their skills to support the group and communication, comprehension, interaction and involvement. Trainee artists are entry level artists, who have not had experience working with adults with PMLD, this gives them the opportunity to be mentored and learn skills fundamental to working with individuals. We are retaining the role within our PMLD groups, as assistant artists, so that they are able to build on their experience within groups.

Appendix

Glossary of terms

PMLD—profound and multiple learning disabilities

LD—learning disability

POA—Pyramid of Arts

LMG—Leeds Museums and Galleries

LCC—Leeds City Council

Active Support—method of enabling people with learning disabilities to engage more in their daily lives Active Support refers to the type of support provided - support that turns person centred plans into person centred action.⁷

Better Together—The Better Together service providers link with other local partners to improve health and reduce health inequality by targeting and focusing support on individuals and groups living in the ten per cent most deprived neighbourhoods in the city.

Leeds Directory—A source of information on a wide range of services and organisations which can be accessed online, by a telephone help line or by printed information in the post. It is funded by LCC.

Clinical Commissioning Groups—CCGs are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area,

there are three in Leeds.

Forum Central—Leeds network of health and social care third sector organisations, which includes Tenfold.

High Support Project (2010-2013)—Big Lottery Funded UPN RC/2/010354666

Normalisation—Normalisation principles require that services be organised to maximise opportunities for the people using them to function with the greatest level of autonomy possible and to have ordinary relationships with the rest of society.

Quality of life conceptual and measurement model⁶—With QOL⁵ assessment, the metric can be subjective appraisal of life events, circumstances, or level of personal satisfaction, or objective appraisal from third parties regarding the status of the person on the life events or circumstances depicted in the culturally sensitive indicators used to summarize personal outcomes (see diagram on this page).

Social Model of Disability—The social model of disability says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

Social Prescribing—A non-medical, community-based

intervention that offers people the opportunity to improve and enhance their day to day lives by accessing support in their local community. Commissioned by the CCGs in Leeds, and operating as PEP (Patient Empowerment Project), Connect Well, and Connect for Health.

Social Role Valorisation—To valorise is to esteem. The label social role valorisation describes the normalisation goal of supporting people (who are at risk of being devalued) to create and maintain a range of valued social roles.

Support Worker—this term covers the difference in name for those who work with the members. This includes key worker, care staff, parents or guardians, personal assistant etc.

Tenfold—Leeds Voluntary Sector Learning Disabilities Forum

Through the Maze—An information and signposting service in Leeds for adults with learning disabilities, family carers and professionals (funded by LCC).

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Quality of Life Framework		
Factor	Domain	Exemplary Indicators
Independence	Personal Development	Personal skills /adaptive behaviour
	Self-determination	Choices / decisions / autonomy / control
Social Participation	Interpersonal Relationships	Social networks, Friendships, Social activities
	Social Inclusion	Involvement in community, Community roles
	Rights	Equal opportunities, Respectful treatment, Legal access and due process
Wellbeing	Emotional Wellbeing	Safety and security, Positive experiences
	Physical Wellbeing	Health and national status. Recreation / physical exertion
	Material Wellbeing	Income, Possessions

High Rise Celebration Day

The Visual Arts group spent the whole of the third year creating a permanent sculpture, which is situated at Leeds Industrial Museum, Armley Mills.

The Movement artists led a parade around the venue to the unveiling of the sculpture. This included musical accompaniment from the Music artists.

The highlights of the Music groups performances were shown in Armley Mills' cinema.

The Sensory and Creative Wellbeing groups showed various art works in the Mills' lunch room, along side photographs from the project over the last three years.







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