The Ripple Effect: Relational Social Care Through Art

Findings Report
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We thank Artlink and Cherry Road Centre for inviting us to collaborate with them.

Thank you also to the artists, Cherry Road, Richmond Fellowship and ELCAP staff and service users who welcomed us to their sessions.

We have been impacted by the process in similar ways to what we have described here and it has been a pleasure and a learning opportunity for us to work on this project.

We would also like to thank Health Improvement Scotland for investing in this important work.
We would like to invite you to be changed by this work, both professionally and personally. In this report, we endeavour to enter a dialogue with you about the ideas and concepts presented here. We hope you are inspired to go on this journey of change.

The collaborative work between Artlink and Cherry Road Learning Centre has introduced a ‘quiet revolution’ (Alison Stirling, Artistic Director, Artlink) in how social care is conceived, practised and experienced. This innovative way of working, which seeks to understand and value people with profound learning disabilities, uses art as its methodology to create aesthetic and sensory experiences that stimulate and excite, in contrast to the monotony of routine and passivity. Together these organisations are challenging prevailing social care practice through developing ambitious, yet achievable and democratic, social care that is co-producing experiences that are immersive and ultimately enjoyable.

Our input as researchers has been through an appreciate inquiry, designed to identify and spread good practice. It used qualitative data to explore the process and impact of the work of artists at Cherry Road. Interpretative Phenomenological Analysis informed the approach to the data, facilitating a deep exploration and exposing the meaning participants attributed to their experiences. Data from reflective diaries and semi-structured interviews were collected over a period of eight months, from June 2017 – January 2018.

Our findings evidence that the innovative and collaborative work between Artlink and Cherry Road is presenting an alternative vision and future for people with profound learning disabilities. The key themes emerging from the data are Art, Relationships, Time and Learning (ART-L). Through integrating art into social care, new ways of working are leading to tangible transformation, improving the quality of life and wellbeing among this group, as well as raising the motivation and enjoyment of social care work amongst practitioners.

The successes of this work have emerged from motivating individuals, giving them permission to work differently and be inspired by their work. This can only emerge when we allow an openness and flexibility within health and social care practice, allowing service users and paid carers to find ways of being, which are meaningful. Current social care policy limits this approach. For instance, a person-centred approach considers the needs of service users but does not fully consider the relational dimension of those involved and therefore the needs of support staff (carers through to management).

Our recommendations are to work with the key themes emerging from this collaboration to enable alternative experiences for service users, paid staff and management. To further expand the element of co-learning opportunities by drawing on the core strengths of the approach.

It has been difficult to display the complexity and intricacy of the approaches adopted by Artlink within current frameworks promoted by health and social care policy. The work described here transcends these frameworks and challenges them. When we use these policy frameworks as a way of evaluating the work there is a dilution in the outcomes. In writing this report we are sharing the Artlink approach and hope to have stayed true to its principles of reflection whilst also and importantly challenging current modes of thinking and practices in social care.
1. Introduction

The current report presents the findings of a 12-month project funded by Health Improvement Scotland to explore the work of Artlink within the Cherry Road Learning Centre, and the impact of integrating art into social care in the lives of people with Profound and Multiple Learning Disabilities (PMLD). The research partnership involved the expertise of University of Dundee and PAMIS academics in conducting a qualitative study and the development of recommendations for use in transforming social care.

Background

Artlink, established in 1984 and based in Edinburgh, Scotland, is an arts and disability organisation promoting the arts as a collaboration between the artist and individual with complex disabilities and their carers. This contrasts with art as a product, accessed through an ‘object-viewer’ lens. Positive change is being realised through Artlink's work and the pursuit of understanding the ‘other’. The openness to challenge and dialogue enables artists to facilitate transformative change in different social care settings, individual sessions and staff training workshops.

Through involvement in art we make connections between people, their experiences and our community - we value people for who they are and celebrate diversity.

(https://www.artlinkededinburgh.co.uk/)

Cherry Road Centre, based in Bonnyrigg, Scotland, is part of Midlothian Council’s Adult Health and Social Care Services, providing innovative opportunities for people with learning disabilities. They promote an ethos of ‘learning together’, the vision of which is to work in partnership with Artlink to enhance the lives of service users. ‘Creating learning environments’ is fundamental to the philosophy and organisational culture of the centre. This is an example of embedding improvement capacity and ‘Creating the Context and Cultures for Improvement to Happen’ (Health Improvement Scotland, 2017:6).

This work is situated within a growing literature on disability and socially engaged art (Levy, et al., 2017, Sinding and Barnes, 2015). It aligns with a social model of health and disability, and an ableist (Campbell, 2009) understanding of the life of disabled people being experienced differently to non-disabled norms (Kafer, 2013), which impacts on how we should conceive, integrate and value disability in social care practice.

This project is unique in applying arts based practice to working with people with PMLD, and is understood to be the first of its kind (Alison Stirling, Artlink Director). For too long normative assumptions of people with PMLD, based on a prevailing understanding of passivity and being non-communicative, have led to this population being one of the most marginalised and excluded in society. The impact of such exclusion from a meaningful life is evident in the existence of poor mental health among this group (Cooper et al, 2007) and disruptions to relationships (Young, 2016).
A small body of work supports the role of social relationships for good quality of life amongst people with PMLD (Petry, Maes & Vlaskamp, 2005), yet opportunities for this group to develop reciprocal and significant relationships are greatly limited (Hughes, Redley & Ring, 2011).

Given the exceptional health and social care needs of people with PMLD, and against their increased vulnerability to the effects of poor care, alternative approaches to meeting their social care needs are urgently needed. Approaches that ensure people with PMLD have access to and receive care and support that is committed and fulfils the principles of prevailing social care policy, along with raising workforce motivation, confidence and competences.

Current social care practice in Scotland is informed by the Social Care (Self-directed Support) (Scotland) Act 2013 and the Public Bodies (Joint Working) Scotland Act 2014. Both call for practice to be person-centred, enable effective and meaningful communication, and to facilitate for service users to co-produce outcomes that enhance their wellbeing and quality of life. The Public Bodies (Joint Working) Scotland Act 2014 provides the legal framework for health and social care integration in Scotland, and the National Health and Wellbeing Outcomes provide the benchmark for the planning and delivery of services (Outcomes 3, 4 and 8 have particular relevance for this project and are highlighted in blue). (Table 1).

<table>
<thead>
<tr>
<th>National Health and Wellbeing Outcomes</th>
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<tbody>
<tr>
<td>1. People are able to look after and improve their own health and wellbeing and live in good health for longer.</td>
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<tr>
<td>2. People, including those with disabilities or long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.</td>
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<tr>
<td>3. People who use health and social care services have positive experiences of those services, and have their dignity respected.</td>
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<td>4. Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.</td>
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<td>5. Health and social care services contribute to reducing health inequalities.</td>
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<td>6. People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being.</td>
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<td>7. People who use health and social care services are safe from harm.</td>
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<td>8. People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.</td>
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<td>9. Resources are used effectively and efficiently in the provision of health and social care services.</td>
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Table 1 National Health and Wellbeing Outcomes
Throughout Scottish Government social care policy, practitioners are tasked with being creative in how they work with and co-produce social care:

*The general principles of the 2013 Act and the aims and intentions behind self-directed support are to provide creative and effective solutions for supported people.*

(Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013, p.73).

The prevalence of reference to creativity in government policy and other areas of professional discourse has led Negus and Pickering (2000: 260) to suggest that creativity has become a ‘dominant category, but a residual concept’, largely understood in economic terms and exemplified in innovative and new ways of working. These are all laudable factors for integrating change into professional practice, however, in the popular rush to be creative, the connection between artistic processes and the affective dimension of creativity are, Madden and Bloom (2004) argue, being obscured. They call for realigning creativity with how art is experienced as affective, that is experienced emotionally.

The affective dimension of Artlink’s work is fundamental to achieving impact in the lives of people with PMLD as well as raising workforce motivation. This approach engages with art as a process that is experienced (Dewey, 1934), is temporal (Llyod, 2014 and 2015), and ‘transforms, if only for a moment, our sense of our selves’ (O’Sullivan, 2010:128). Conceptualising art as experience that achieves affect over time is the foundation upon which the lives of people with PMLD are transformed at Cherry Road Centre. And is the foundation upon which this work is person-centred, gives a voice to service users, and is collaborative, with Artlink artists working closely with service users and staff from Cherry Road and other community support organisations. Furthermore, the collaboration across organisations has a strong foundation in active leadership by Cherry Road management and an openness to embrace and successfully achieve organisational culture change.
2. Methods

This was an appreciate inquiry designed to identify and spread good practice. It used qualitative data to explore the process and impact of the work of artists at Cherry Road. Interpretative Phenomenological Analysis informed the approach to the data, facilitating a deep exploration and exposing the meaning participants attributed to their experiences.

Artlink Sessions

This project is based on four artists working with four service users and their carers. The artists worked with the service users in the following ways:

- One-to-one work: one artist collaborating with one service user and one carer. This approach was used with two of the service users, these sessions were both located at Cherry Road. One of the service users had carers based at Cherry Road. The other service user had a personal assistant (PA) that they employed through Self-Directed Support.
- Group work: two artists collaborating with one service user and one or more carers. This approach was used with two of the service users and these sessions were held outside of Cherry Road, one in a local swimming pool and the other in a large community hall. The carers for one of the service users were based at Cherry Road, whilst the carers for the other service user were employed through a voluntary agency, and there was a change in provider during the project.

Data Collection and Analysis

Data from reflective diaries and semi-structured interviews were collected over a period of eight months, from June 2017 to January 2018 (Table 2).

<table>
<thead>
<tr>
<th>Participants</th>
<th>Reflective Diaries</th>
<th>Interviews</th>
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<tbody>
<tr>
<td>Artlink Artists Staff</td>
<td>Artlink Artists Staff</td>
<td>Artlink Artists Staff</td>
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<tr>
<td></td>
<td>Cherry Road Management</td>
<td></td>
</tr>
<tr>
<td>Sample Size</td>
<td>Artlink Artists x 59 Staff x 52</td>
<td>Artlink Artists x 4 Staff x 3</td>
</tr>
<tr>
<td></td>
<td>Cherry Road Management x 2</td>
<td></td>
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<tr>
<td>Total</td>
<td>111</td>
<td>9</td>
</tr>
</tbody>
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Table 2 Data Collection
Early observations of Artlink sessions and conversations with the artists and management at Cherry Road led to the development of a Reflective Diary template for artists and staff to complete after an Artlink session (Appendix 1). We use the term ‘staff’ from now on in the report to refer to paid carers supporting service users, reflecting the language of the study participants. The Reflective Diaries provided the artists and staff with trigger questions to reflect and comment on three key areas:

- Benefit/Impact
- Transformative Moments
- Learning/Self Development.

All four artists and sixteen staff completed reflective diaries. The number of staff is indicative of the range that were involved with the four service users. The reflective diaries documented multi-dimensional change over a period of time, including evolving relationships, especially for those new to working with each other. The reflective diaries stand as testament to the impact of the Artlink sessions on the lives of all participants, and as a useful tool for staff development.

Initial analysis of the reflective diaries informed the questions for the semi-structured interviews with artists, staff and Cherry Road management (Appendix 2). The interviews focused on four key areas:

- Artlink Sessions
- Collaboration/Shared Learning
- Impact
- Research Process.

The interviews were recorded, transcribed and along with the reflective diaries uploaded into NVivo (qualitative data analysis software package), allowing for thematic analysis of the data, framed by Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2013).

Other than references to Artists and Managers, pseudonyms have been used throughout this report to protect the identify of individual service users and staff. Ethical approval for this project was received from the University of Dundee Ethics Committee.
3. Findings

So much social care replicates ordinary life for people with PMLD. It should be creating a life that stimulates the individual, exploring new experience and opportunities.

Liz, Manager, Cherry Road Learning Centre

People with PMLD are some of the most marginalised within society. Unless we change the lens through which we understand them, they will continue to be seen as passive and non-communicative, with the risk that current social care practice will persist in reproducing the status quo. The collaborative work between Artlink, Cherry Road Centre, service users with PMLD and their families is evidencing an alternative future through redefining social care and in doing so, this work is aligning with but also evidences the limitations of current social care policy.

The project findings are presented in two sections. The first evidences good practice of current social care policy:

- Person-centred
- Communication
- Co-production.

The second section explores the four key themes emerging from data analysis that will fully capture the relational dimensions of the meaningful experiences that are afforded by this approach:

- Art
- Relationships
- Time
- Learning.

Each of the four themes contributes to explaining the success of the Artlink work at Cherry Road, and establishes the context for achieving impact and for transforming current social care policy and practice.
Evidence of Good Practice

Person-Centred

The Artlink sessions were positioned as person-centred and facilitated choice, control and agency in the lives of service users. The artists understood time spent with each service user in a unique way and were open to each session being a new experience. Pre-planned expectations were not imposed, rather the genesis of each session evolved from the service users’ interests, levels of arousal and capacity. Interactions were responsive to the individual service user and experienced as stimulating, immersive and reciprocal. These experiences typically contrasted with familiar patterns of social care, with stimulation replacing the mundane, and agency with passivity.

It was evident that the Cherry Road management are providing leadership when interpreting ways of applying person-centred practice to make it relevant and meaningful:

Sometimes...people will be offered a choice of different services, or opportunities, and they don't understand because the choices aren't presented in a way or in a format that's understandable. People will choose to do nothing due to the lack of information or experience. So...the true meaning and values of social care often get lost in translation.

(Liz, Manager, Interview)

Salient to this approach was offering flexible solutions to apply policy in practice.

“I don’t want to dance today”. You can come away from that and say OK right, we have outcomes that have been set that are about keeping you mobile. But we don’t have to dance or do sports, we can we sit and gently move together and spend time ... I think its about the personal qualities.

(John, Team Leader, Interview)

Agency was visible through service users exercising choice and control at a macro and micro-level, from shaping and influencing a whole session, to choosing the type of beads to be used within an activity.

I think he benefits from it in different ways. He’s taking a lead role, so he’s deciding what he wants to happen in the activity, he’s got control over what happens ... he doesn’t follow us, he actually takes the lead so he goes in and gets the hall ready for what he wants to do that day. Which is totally different.

(Staff: 1, Interview)

I just think it is quite amazing how he can focus and how he can make this (joy
Empowering people with PMLD to lead activities and articulate what they wanted to do was perceived as innovative, ‘amazing’, and a new way of enacting social care for the staff. Through working closely and collaboratively with service users, the artists and staff are exposing and understanding the person behind and beyond their disability.

* I think the disability dissolved once we’re all communicating really well.  
  
  (Kevin, Artist, Reflective Diary)

This work has stimulated conversations on changing perceptions and expectations around disability, of being open to alternative forms of potential and different ways of experiencing the world. In essence, the work is challenging the discourse of social care to see beyond the perceived limitations of a section of our population that have very few positive attributes ascribed to them.

*Communication*

Communication is the foundation upon which relationships are built, and time was taken to build this foundation in the Artlink sessions. Artists described their relationship with service users as a process that emerged through collaborative play, experimentation and affect. In the words of one of the artists, ‘I’m very much trying to reach somebody.’ Time spent experimenting and playing with different approaches continued until the artists were able to open a dialogue, a conversation with their service user. Awareness of using alternative forms of communication, draws the artists and staff more intimately into the sensory worlds of people with PMLD and other ways of being and seeing the world. Importantly, for the staff they highlighted how they were ‘able to have fun with him (service user) without using words.’

* His (the artist’s) ‘conversation’ with him (service user) was brilliant. He uses his body and objects to converse. It’s quite powerful to see. I think all the staff were quite amazed to see how communicative he (service user) was in his own way and how much fun he was having.  
  
  (Fran, Artist, Reflective Diary)*

* Doing things a lot slower, and obviously spending time just to be quiet and maybe not speaking for say a few minutes and then seeing how Penny asks you a question, instead of it always being you asking the questions. So that is something that I’ve learnt from them.  
  
  (Staff: 3, Interview)*

This project demonstrates, in the narratives around communication, that:

- people with PMLD can communicate, but time is required to identify what forms of communication enable connections to be made with each individual
Artlink artists are skilled in connecting with, experimenting and identifying ways to communicate with people with PMLD that enables the voice of the service user to influence outcomes in their lives, and for the staff to learn through this process.

Equal to the approach of the artists are the facilitators of the work. The managers at Cherry Road have demonstrated leadership and role modelling, through ‘giving permission’ to artists, service users and staff to experiment with ways of connecting and communicating. Management have a clear strategy to embed art into the social care and culture of the centre. Service users and staff are empowered through their creativity, which shifts the balance of power from management to an equal sharing and sense of agency in the individual. For example, it is when service users and staff are permitted the freedom to express this agency that connections with service users are established:

We would never scoff at somebody for trying to be creative or trying to do something different, we actually promote and encourage that ... She (staff) was new to working with a service user with relatively complex needs. She had done all the functional things that everyone else had. She had mentioned previously that she had wanted to do some yoga and relaxation classes. So I said, “Do you want to try some breathing, gentle yoga type exercises with the service user.” She came back and said, “I got such a connection!” I feel like it was a type of ‘giving permission’, because there’s nothing like that in the guidelines...She discovered something (about the service user) that I would never have discovered.

(John, Team Leader, Interview)

Co-Production

One of the challenges of applying current Scottish social care policy is co-producing outcomes with service users who are perceived to have limited communication. Furthermore, a focus on person-centred approaches can eclipse the role of collaboration in achieving outcomes that can impact on the wellbeing and quality of life of service users, staff, and in this case, artists. Collaboration is a cornerstone of the Artlink work which facilitates democratic and reciprocal working between artists, staff, service users and their families. In the words of one of the staff, ‘everyone’s included in the session’.

This project reveals collaborative practice as co-producing outcomes for service users, but also for staff which appeared to be impacting on their overall motivation and work satisfaction. Within the staff narratives there were frequent references to collaborative working. They articulated that they felt included in the Artlink sessions and they perceived their role in the sessions as having been significant in the transformational change that was visible in their service users. This demonstrates a confidence in their contribution to the impact of the Artlink sessions.
Just giving ideas, different things that I’ve experienced with Chris, I’ll pass onto him (artist), and he’ll say I’ll see what I can do with this, if I can tweak this …. so yes yes, we work together definitely.

(Staff: 2, Interview)

We sort of talk a lot and she’s (staff) good. If I ask her questions, and her input, I mean her input is invaluable.

(Laura, Artist, Interview)

From the artists’ perspective, they were keen to highlight how they were involving staff in discussions about the sessions. Through this dialogue it was evident that the artists were supporting staff on their learning journey to understand and embrace new ways of working, and to get ‘it’.

The staff today just got it (the elusive “it”) …

(Steve, Artist, Reflective Diary)

There appears to be respect for the eclectic roles, identities and contributions that are brought together in the Artlink sessions by the artists, staff and service users, and an appetite to learn from each other. This diversity was manifestly complementary, with each contributing something unique to achieving impact.

One of the strengths of the Artlink-Cherry Road collaboration is how the different professions (art and social care) are valuing professional differences to learn and work together. As a profession, social care staff want to feel ‘safe’ in their practice. However, being and feeling safe can bring with it an element of predictability, control and ownership of what is going to happen, which can result in practice being carer-led. In contrast, artists have greater freedom and situate themselves in vulnerable spaces, unsettling the ‘safe’ to provide opportunities for new experiences. The Artlink-Cherry Road collaboration has successfully negotiated a dual space, which provides safety alongside vulnerability. Our findings point to these dual spaces as stimulating, enjoyable and empowering. For staff, artists and service users this approach to social care is challenging them to embrace moving out of their comfort zone and into the unknown as an opportunity for transformation, self- and service-user development and for co-producing outcomes:

A space which is fluid and where…there’s possibilities.

(Steve, Artist, Interview)

The thing I love about Alison (Artistic Director) is she just has this faith that you just have to jump into it and you have to. That's kind of really helped me approach the work in that way and not be afraid of that because sometimes you're a bit like what's going on? But that's just kinda how it is. You can’t.

(Laura, Artist, Interview)
This dual space is contrasted with more typical social care where spaces are already ‘constructed’ and ‘patterned’, and where care staff may be devalued. Certainly, the novelty of the social space that is created within the Artlink sessions brings a fresh perspective for all those involved. In some cases, it was important to inhabit other spaces outside of the Cherry Road (community hall, swimming pool) where there was, in the words of one of the staff, ‘less distraction’ to explore new possibilities.

**Themes Emerging from the Data**

*Art*

When reflecting on the role of art, artists, staff and managers all referred to the process of working with another, fashioning relationships and creating space. Art was understood as an experience, involving the senses and the whole body and mind. Experimentation and collaboration are key ingredients to this creative process, which involves the service user in co-creating the interaction and interactive space:

> We’re not making objects we’re generating experiences through time. That’s the art. And the art aspect is process, experimentation, but art and art sensibility allows a huge openness of possibilities.

(Kevin, Artist, Interview)

This redefines our concept of creativity and adds to it an understanding of ‘encounters’ as a process in art, a playful shaping and re-shaping of communication through experimentation to create relationships. Initially, a ‘stripping back’ of already established structures and ways of interacting are necessary to promote openness and an equal space to meet and learn about the other:

> What you’re trying to do is go back to a very simple blank canvas and introduce elements.

(Fran, Artist, Interview)
None of the artists or staff reported their experiences of the sessions in terms of outcomes:

"I never really thought about it, it’s quite a strange question actually….. it’s like they’re coming along to spend time with Penny, it’s just like they’re a friend."

(Staff: 3, Interview)

Artists adopt an interesting approach of having no fixed expectations of the service users, which subverts the practitioner-client relationship that typically involves goal-oriented interaction. Sessions were instead seen as moments to enjoy and embody and this is consistent with how the work is conceptualised:

"How do I approach the sessions? erm, with no expectation. I think when I started at Artlink, I always tried to plan, pre-plan and have an idea in my head about what the workshop would be like. I think over time as I’ve became more experienced and familiar with the type of work that we do, actually there’s no expectation..."

(Steve, Artist, Interview)

"For me that has been the biggest part of my learning… the ‘not having the formula’. Nor is it about ‘going with the flow’ because that can be quite aimless…or having a strict agenda for what we’re setting out to achieve. It’s more about the quality of finding out about each other."

(John, Team Leader, Interview)

There was a coherent vision for blending art as experience into social care within Cherry Road practice, so this approach was not linked to specific work of the artists, but as an approach adopted by staff and embedded within the culture of the organisation:

"No-one really ‘likes’ physio…. how do you motivate people during their physio sessions… so for people who have to stretch on the floor and move..."
around...we’re thinking about ways in which it could be a more enjoyable sensory experience ...like lying on a big patchwork quilt with lights or furry tactile things.

(Liz, Manager, Interview).

Art is conceived here as the process of ‘awakening’ someone, activating them and motivating them to move, and not about the physical object. Arousal modulation is a key consistent approach within the practice and we discuss this further in ‘Relationships’.

Relationships

Artists and staff described their relationship with service users as a process and this very much emerges from collaboration, including other aspects discussed later here (e.g. experimentation and affect):

It’s been kind of interesting to understand Violet and how she interacts with, and how she sits in a group and, so it’s been sort of lot of observing and thinking ‘should I really be doing this?’ but actually it’s been really valuable for us getting to know each other and sort of forming a bit of a friendship...And I think that’s been a really good part with Violet, that she sort of trusts me and she will try things and we can be a bit more ambitious.

(Laura, Artist, Interview)

He [service user] takes the lead.... he benefits from it in different ways. He’s taking a lead role, he’s deciding what he wants to happen in the activity, he’s got the control over what happens.

(Staff: 1, Interview)

To a large extent, these accounts inspire a redefining of relationship. Vulnerability and humility establishes a more equal relationship for two individuals to meet. Reaching a place of vulnerability was experienced through lack of knowing the individual, questioning the self and what you were doing, trying to be open and using yourself as material through experimentation, even if that meant behaving in ways that looked ‘silly’ to others.
The subjectivity of the service user may be further understood with reference to changing perceptions of disabilities, and re-making of relationships:

Watching people develop the skills and confidence in these workshops, it’s almost like we’ve had our eyes closed and we haven’t seen the person.

(Liz, Manager, Interview)

An important part of the dyadic engagement is the identification and modulation of affect (emotion). The artists are particularly attuned to the arousal levels of the service users and sensitively make changes in their practice to explore fluctuations in these arousal levels, in order to find the optimal place for regulation, growth and development. A sensitivity and presence is required to effectively do this. Whilst it is unclear whether staff were practicing this approach before the involvement of the artists, it is clear that staff are demonstrating arousal modulation:

When I see Chris getting bored and it’s getting too much, I’ll say, “try something different...”

(Staff: 2, Interview)

Being able to respond to individual differences involved an awareness of small and very subtle movements or changes, also appreciated by management:

For me it’s about how we go about discovering things...Working with Artlink and working with the service user groups.... it’s about the subtleties of what would be happening.

(John, Team Leader, Interview)

And the signposts for guiding these interactions are in the detail, looking – really looking – for a change in affect and arousal level. Maintaining an optimal level of arousal through stimulation was seen to be a crucial aspect of learning and presence for service users, recognised by both artists and staff.
Artists and staff report a huge sense of well-being relating to their work with service users. An important point to highlight here is the significance of being affected by the work that you do. This speaks to issues of equality, where both the service user and practitioner – staff – give and receive, inherently motivating them to continue learning about each other and raising levels of satisfaction:

...we were like, OMG we’re really going to have fun. We would never dream of doing all of that...it’s more relaxed and just good. It was an activity that we looked forward to...

(Staff: 1, Interview)

...we played a pop song but slowed it a little bit, and I was singing to him and what a reaction we got, just doing something different. I had a lump in my throat...

(Staff: 2, Interview)

Management also reflected this insight of valuing and responding to the needs of staff:

I think there has to be consideration to both. I’m a great believer in remembering that in social care, social care providers and social care recipients of social care, belong to the same species and have the same needs. An organisation that has exceptional values about being person-centred and highly valuing the service user, should also value their workforce.

(Liz, Manager, Interview)
Time

Artists and staff understood the concept of ‘slowing down’ time. The significance of time was not simply slowing down activities, but rather ‘stretching experiences’ qualitatively as well as temporally. This was seen to be facilitated by a ‘loss of time’ or an absence of measuring time. In other words, presence and mindfully staying in the moment were significant:

it really affected me the rest of the day, that feeling of being both present/lost in a moment/grounded/calm stayed with me. I’m conscious that what I’m/we’re doing might be something similar to ‘mindfulness’ or meditation and I am questioning if this is right? But these moments of deep/intense experience feel right for just now.

(Steve, Artist, Reflective Diaries)

Doing things a lot slower, and obviously spending time just to be quiet and maybe not speaking for say a few minutes and then seeing how Penny asks you a question, instead of it always being you asking the questions.

(Staff, 3: Interview)

Slowing down time also involved a letting go of controlling the session, a relinquishing of this tendency and typically established interaction:

It’s that ability to be observational and still and quiet, rather than always directing.

(John, Team Leader, Interview)

Such an approach led to relational moments:

it’s not just about the activity, it’s about this element between us and having real time with someone else.

(Laura, Artist, Interview)
Learning: Unlearning and Co-learning

There appears to be a continual seeking within the artists, for an understanding of the individual.

Learning was focused on relationships; learning about each other and how to ‘be’ with another. One of the learning outcomes consistently shared by the artists was the understanding that people with a disability have a strong internal world, that the external world is often threatening for them and that they may in fact process and perceive the world in entirely different ways from non-disabled peers:

*I think through working with people with a disability is another way of seeing the world because I would not have come across this level of perception right from undergraduate philosophy and trying to understand the world, but I've learned a lot through being with disabled people.*

(Kevin, Artist, Interview)

Learning about another was described as experiential through the process of relationship building, and not solely through cognitive knowledge. To understand this is to embody it in their continually changing interactions with the service user. For one artist, their connections with the service user prompted them to ask questions about themselves and what teaching may also lie there:

*What is working with Penny revealing about myself?*

(Steve, Artist, Reflective Diary)

Learning was not limited to the artist, but extended to the experience of the staff. There is clear evidence of the impact of the artist’s way of working on staff:

*I think slowing down is important…so that is something that I’ve learnt from them…*

(Kevin, Artist, Interview)
It’s about being creative…. learning… I like to learn different things, get different ideas… it’s like ‘oh, I never thought about doing that’.

(Staff: 2, Interview)

Reflecting the general approach adopted within the project, the traditional teacher-student didactic relationship becomes dialogical through shared learning experiences. Management were keen for staff to have these opportunities:

to give people the opportunities that I’ve been so fortunate to have, in my career, other colleagues didn’t get the opportunities to work with the people that I have learnt from …. So how do I give new workers the opportunities that I’ve had? How do I pass on what I’ve gathered? This is done through one-to-one mentoring, tutoring as well as talking, but also through giving permission to take chances.

(John, Team Leader, Interview)

We introduced a series of blocks of workshops where staff and Artlink artists work together with service users. In these workshops both the staff are challenged as well as the service users. Those workshops have helped to really build the relationships between the service users and the staff and it transforms through a shared sense of vulnerability into a companionship. It changes the dynamics of the relationships between the staff and service user.

(Liz, Manager, Interview)

Finally, the added dynamic of being researched contributed to the artists and staff’s sense of vulnerability. However, overall they experienced this as greatly positive as it encouraged them to reflect on their work and there were suggestions for integrating the use of reflective diaries into their practice.
In the spirit of collaboration staff at Artlink, Cherry Road and the University of Dundee have worked together to conclude the findings of this research. It is an amalgam of opinions, talked over, thought about and added to. A reflection of the project itself. This innovative way of working, which seeks to understand and value people with PMLD, uses art as its methodology, to create aesthetic, sensory experiences that stimulate and excite people with PMLD, in contrast to the monotony of routine and passivity. This relational approach offers creative and new ways for social care practitioners and family members to develop meaningful social care that connects with service users on their terms, in a time and within a space that has meaning and value to them, enabling them to have a voice and some agency in their lives.

Building appropriate packages of care for people with PMLD can often be an overwhelming challenge for social care professionals, with people on all sides making demands. This can become confusing and make it harder to build care plans that are of longer term relevance to the individual and their support systems. So how do we ensure the individual with PMLD has an impact on wider care systems? How do we use their involvement to plan for the longer term? How do we create environments in which people are listened to and learned from? How do we use creativity to promote greater equity of involvement? The answers to these questions cannot be found in a ‘one size fits all’ approach but are down to how all involved in caring choose to listen to each other, learn and work together. It is essential that creative, innovative and collaborative ways are used to meaningfully engage and inspire not only the service users but the wider support structures around them – carers, families, and other representatives whose creativity/specialisms are of relevance.

The work of Artlink and Cherry Road recognises that meaningful experiences are achieved through slowly building authentic and genuine connections. Working with the artist inspires creative thinking which motivate to create a ‘safe’ space where all can work together equitably, learning from each other; opening themselves, and those they work with, up to new experiences and perspectives. This informs:

- A greater understanding of the person with PMLD, through identifying a simple, achievable goal to work towards.
- An environment supported by people who choose to work together and sharing ideas.
- Creative thinking which expands interpretation and understanding of individual needs and developing interests.
Rather than presenting a list of recommendations we are presenting a short list of questions for reflection that can equally be used for expanding of co-learning opportunities through staff development and training. We ask that you consider each question within the context of this report and the collaborative practice between service users, Artlink and Cherry Road. Take time to consider the emotional and relational dimensions of your responses and ways to achieve affect and effect within social care.

### Questions for Reflection, Discussion, Collaboration and Learning

1. Do you know what motivates and interests the individual you work with?

2. Are you employed or supported by agencies or statutory services that have courageous and enlightened leadership?

3. Do you work as part of a team? Can this team set achievable goals to work towards what motivates and interests the individual you work with?

4. What links to people, ideas or activities can you make for the individual in relation to their developing interests?

5. Do you feel able and confident to continue to travel on a journey of change, to experiment and explore ways of working that come directly from the individual you work with?
The following table offers a summary of how the impact of this work aligns with and achieves Outcomes 3, 4 and 8 of the National Health and Wellbeing Outcomes.

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Evidence of Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. People who use health and social care services have positive experiences of those services, and have their dignity respected.</td>
<td>This project evidences how meaningful engagement positively informs care structures and ways of interacting that are necessary to promote openness and an equal space to meet and learn, creating a service that is more flexible and respectful of people PMLD’s developing interests.</td>
</tr>
<tr>
<td>4. Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.</td>
<td>This project evidences how integrating creative thinking and practices into social care, positively impacts on the lives of people with PMLD, increasing their ability to communicate, exercise agency and take greater control in their lives. This leads to tangible transformations which improves the quality of life and wellbeing among this group.</td>
</tr>
<tr>
<td>8. People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.</td>
<td>This project evidences that the use of art in social care is raising the motivational levels of carers along with job satisfaction, and that this happening within a positive learning environment.</td>
</tr>
</tbody>
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References


Appendix 1

Reflective Diary Questions

Name:
Artist:
Service User:
Carer:
Date and Time of Artlink Session:

Benefit/Impact

1. Describe the dynamic (key exciting moments) within today’s session. Between you, the service user and the others (carers/artists).

2. What did you learn about your service user and the others (carers, artists)?

Transformative Moments

1. Describe the key interactions in the session. Were they between you and your service user? Between others in the session? Describe.

2. At what point did you stop thinking about what you were involved in and just participate? Describe.

Learning and Self-Development

1. Describe in three words what you learned today?

2. What has the work helped you to think about, look at or change?
Appendix 2

Interview Questions: Artists

Note: there was slight variation in the interviews with staff and management

1. In your own words can you describe the Artlink sessions at Cherry Road?
2. What are the principles underpinning your work?
3. How do you experience the sessions?
4. What do you get out of working with the service users and artists?
5. How do you think the service user experiences the sessions?
6. What does art and being creative mean to you?
   a. What is the art in the sessions?
   b. Do you think of yourself as creative?

Collaboration/Sharing Learning

7. What conversations take place between you and the staff about the sessions?

Impact

8. What is the impact of the sessions?
9. What leads to the impact?
10. What have you learnt from what is happening in the sessions?
11. How do you think the work of the artists can be translated to other professional practice?

Research Process

11. What is your experience of the research process?