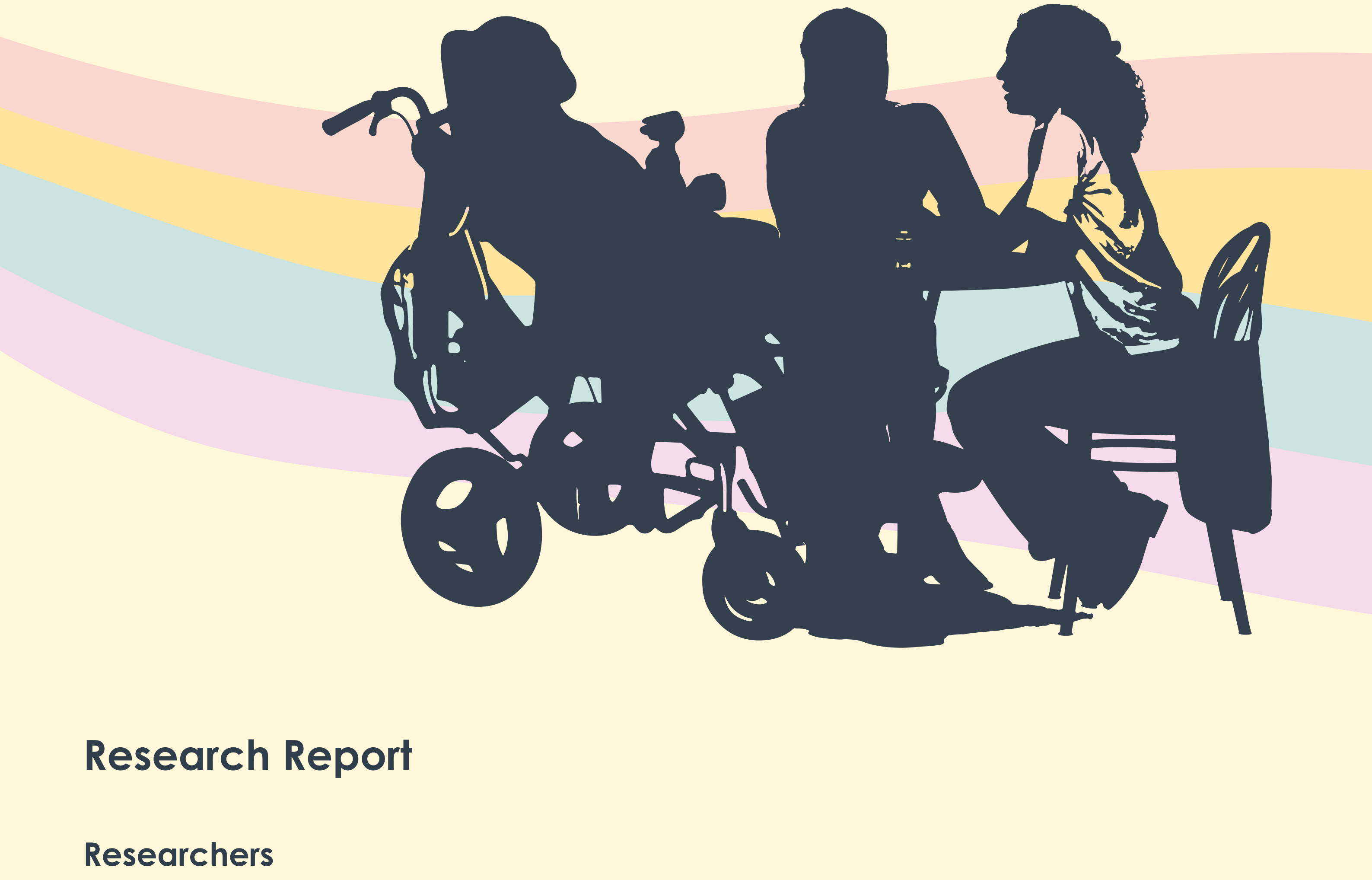
Something's got to change:

Listening to the stories from families and allies of people with profound and multiple learning disabilities



Research Report

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We Are The People
Bath Spa University

This report shares the finding of the profound and multiple learning disabilities strand of research from the We Are The People project, a 5-year research project led by disabled researchers and non-disabled allies in the South West of England, funded by Wellcome Trust.

The project's work centres disabled voices, experiences, and leadership in shaping research that matters. Using creative, inclusive, and participatory methods, we challenge traditional research hierarchies and open up new ways of knowing and doing.

Empathy

The system and professionals

Our people (adult children) are valued, loved, lovable and loving

Time and the future

Many themes emerged during our conversations, all of which would warrant exploring further. This report shares the themes that were talked about the most, but all themes weave together. The themes are presented in the report in this order at the request of the participants.

“Most of the time the universe
speaks to us very quietly;
In pockets of silence.
In coincidences; In nature;
In forgotten memories;
In the shape of clouds;
In moments of solitude;
In small tugs at our hearts”

Yumi Sakugawa,
Artist

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Introduction

This co-produced research has been made possible because of the generous time spent with families, carers and supporters of adults with profound and multiple learning disabilities (PMLD) in the South West of England. Becky Churchill is an artist and community researcher and Katie Crouch is a Senior Lecturer and Research Fellow, who both have lived experience of disability and living with children with special needs. The project has also been supported by Dr Katy Brickley, a Postdoctoral Research Fellow at Bath Spa University.

We spent time with families who all have adult children who either have PMLD or severe and complex learning disabilities. We were particularly interested to speak to the family members of adults with PMLD, as we wanted to contribute to the sharing of their stories.
As researcher, Dr Karen Healey states,

'Stories change us; they change the world.
People are the stories of themselves'.

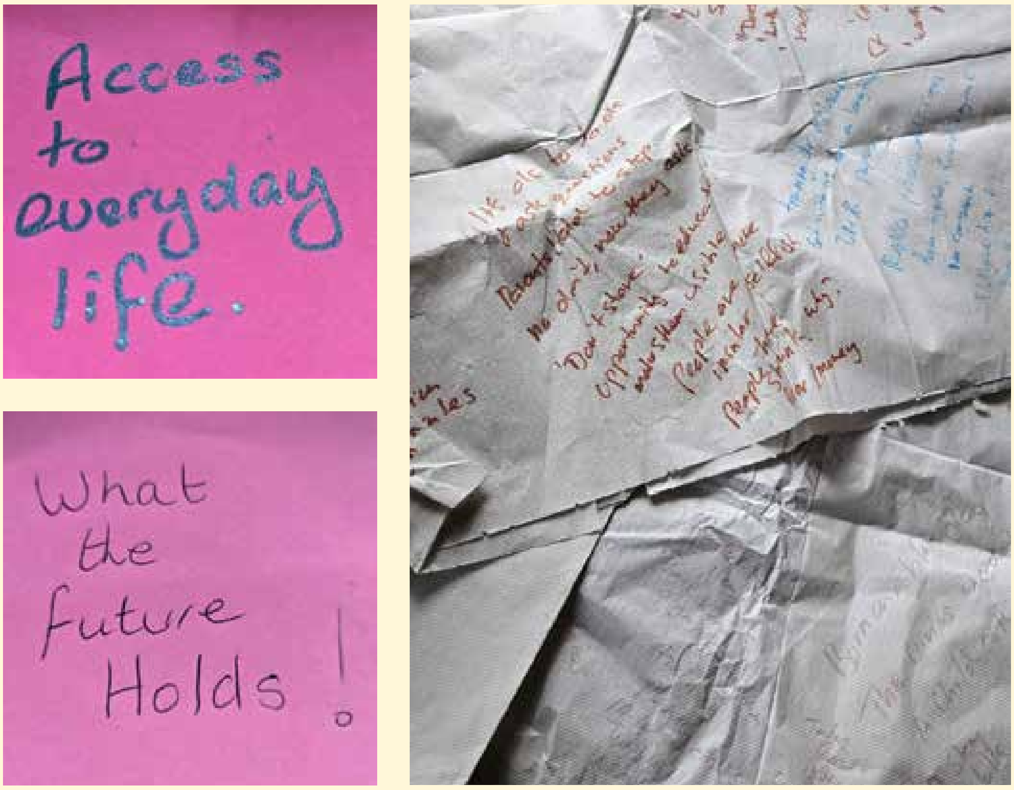
We thank the parents for letting us glimpse their worlds and the richness of them, albeit for a short time.

This research team had hoped to collect the stories directly from adults with profound and multiple learning disabilities. The conversations that arose from this ambition made us realise that, to collect the stories, we would have to talk to those who didn't have a learning disability. We would have to talk to parents, siblings, allies and carers to be able to hear them. Under the Mental Capacity Act (2005), any university research involving adults with PMLD requires NHS research ethics approval, which is a lengthy procedure and not something we could have attained within the life span of the project. Whilst we could meet people with PMLD, we could not collect research data from them during this project due to these ethical constraints.

In place of collecting stories directly from people with PMLD, we relied on the expert knowledge of families and carers. In a 6-month community research project, we didn't have the necessary time to get to know people with PMLD well enough to understand their unique ways of communicating, including how we reciprocally speak and listen to each other. This was an important fact to hold in mind. The ethical system - designed to protect research participants - also disabled us from gathering their stories.

Many themes emerged during our conversations, all of which would warrant exploring further. This report shares the interlinking themes that were talked about the most.

We didn't take on board the contradictions of terminology, except that it is about people with profound and multiple learning disabilities, which covers a broad range of syndromes and conditions under the umbrella of PMLD.



Notes from the first coffee morning.

Approach

Our research question was

‘How can lived experiences and social histories of the PMLD communities be best collected, curated, and shared?’

We gathered as a group of up to 16 people as a drop-in over four weeks. We were parents, foster parents, staff from a local PMLD daycare, and researchers. We knew this group could potentially feel isolated, and any formal questioning be off-putting, so felt that holding a coffee morning would feel less formal. For most parents this was time to be sociable, as well as share stories. We acknowledge that for some participants, the coffee mornings were difficult to attend due to distance and time. This meant that with some parents, due to the distance and shortness of the day, they only came once. Their sons and daughters were attending the day centre between 10am and 2pm, so the two hours of meeting and the travel took out the whole day.

We took notes, recorded the conversations, used mind maps, drawings, and looked at parents’ personal collections (e.g. photos and medals) to inform our findings. After the research team analysed the transcribed recordings, and noted themes in the discussions, we checked with our participants if they felt we had represented the views expressed in the coffee mornings accurately.

The parents were asked to informally discuss their experiences of being a parent/carer who have adult children with PMLD. We asked about the theme of friendship as an opener. This reminded many parents of how much easier it was to make friends when their children were younger. It was easier to move and travel when the parents were younger and fitter and could carry their child.

Holiday stories were shared and clubs talked about where families travelled as a group. However, conversations quickly turned to how things are very different for our families now. Navigating life and holidays with an adult with PMLD isn't as easy as it was back then.

Participants agreed with our framing of their experiences and were keen to present the themes in the following order.

Reflect
Refreshments
Research

Are you a parent, family member, carer, or supporter of an adult with PMLD?

You are invited to join us for a friendly coffee morning, where you can take part in our research project and share your stories.

Coffee morning information flyer.

Theme of:

Being valuable, loved, loveable and loving

The parents stated that if their sons and daughters were truly seen by institutions and the individuals within them, this report and the research wouldn't be needed. Everybody is valued whatever their disability. Everyone is valued, worthy and loveable. Everyone is an essential part of our humanity. It is up to the people who can, to use whatever means necessary to make our environments accessible, to make our attitudes inclusive, compassionate and accepting so that this doesn't need to be the parents' fight anymore. They have taken part in this research because they love their children deeply. A good life for them is where everyone thrives with systems of support that listen.

Parents reported wanting their sons and daughters to be free from experiencing exclusion, invisibility, and tokenism, and that empathy not sympathy should be at the core of all interactions. Parents described how true human value is not found in the documents and forms that they must fill in on a regular basis.

Improvements in neonatal care and access to medical treatments, are enabling people with PMLD to thrive beyond previous expectations. While this represents huge progress, parents were keen to stress that the need for support doesn't stop when they left the hospital with their babies. These parents want us to know that they not only love their adult children, but represent them, keep them alive, and are their voices. They are celebrated:

‘[My daughter] loves having her nails done … she’s got boxes of nail varnishes. […] She loves watching canal boats.’ (Mother, participant).

‘[My son] likes football - the football results.’ (Mother, participant).

‘So [my daughter] is a traveller, she enjoys preparing going on holiday, loves the car. […] She enjoys musicals and concerts, and at Christmas we took her to see Moulin Rouge in London… She had been fast asleep the whole day … as soon as the music started, she was awake and absolutely fixated on it… just really really enjoyed it.’ (Mother, participant).

‘[My son] is a delight. He has a good sense of humour and is very loving.’ (Mother, participant).

The parents want these stories of love to be out there to change peoples’ attitudes.

‘My whole life has been revolved about keeping [my son] alive because of his seizures. […] I’ve tried holidays and I’ve spent the whole holiday in accommodation with [my son] having seizures because he couldn’t cope with a strange environment. So, you evolve, and you have to enter their world, and that’s where it has an effect on you as parents, because you lose your life accommodating the children. […] And we wouldn’t have it any other way because these children, for whatever reason are... I still don’t understand the magic spell they have over us but they’re more precious than anything. The love that they give is immeasurable.’ (Mother, participant).

Theme of:

Professionals and the system

The parents shared stories of professionals and the system. This theme emerged as a shared frustration with the system and bureaucracy being hard to navigate. This was the largest and most talked about of all the themes collected.

The parents spoke of what they wanted professionals to know, and what they would tell them if given the opportunity. The parents wanted to plant a seed that will start to grow to challenge the system and grow into social change. Many parents believed this change needs to come from the top down, as they are the people who control and manage the money.

'I think it has to be the people at the top, but it also has to be society much more broadly.'

(Father, participant).

The parents spoke of how their family life is tied up with the navigating systems of various organisations, including the NHS, social care and social work, GPs, Department of Health and Social Care, Court of Protection, Department of Work and Pensions, Somerset Council, the Care Quality Commission, all professional bodies of General Medical Council, Nursing and Midwifery Council, Health and Care Professions Council, etc. This navigating included working out who funds care.

Parents spoke of constantly having to follow systems and procedures that are not created for their adult children, which meant they had to decide to go along with knowing it's not right, or challenge these systems.

One mother in the group remarked that their days were spent attending to their adult children, just as they did when they were babies. For these parents, these tasks never end. **'We must adjust'**, she said. She relayed how they can take them to a doctor's appointment only to find the surgery does not have a hoist to allow for examination. She felt they had to challenge every aspect of life **'that just doesn't work for us'** (Mother, participant).

One parent voiced the view of all participants:

'You can just get pushed in a direction where you actually know it's not right, but you can't do anything about it because you're having to follow a path created by somebody else who hasn't listened'.

(Mother, participant).

Parents spoke about how as their children aged, they wished for the organisations which 'overshadowed' their lives to know what their life was like, so that these systems became empathetic rather than negative. Parents spoke of how they wanted organisations to work together to help share needed information and support with themselves.

'The authorities will tell the courts they've taken the family's feelings into account but what they do is make a decision and then present it to the family. It's all back to front.' (Mother, participant)

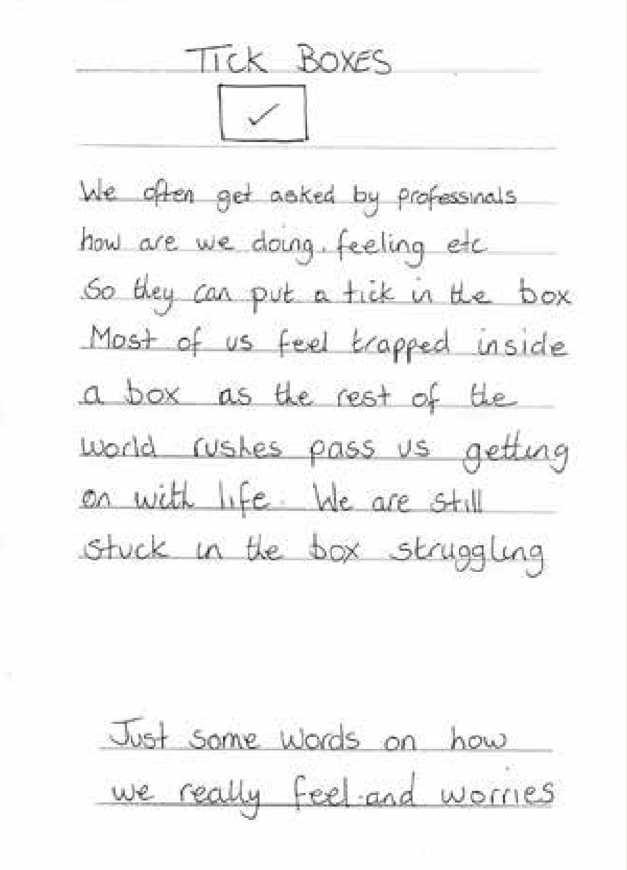
Becky, our community researcher, paraphrased in her own words the discussions that were had during a coffee morning:

‘There is so much paperwork. Sometimes such large documents to fill in. There is so much jargon and legal jargon that we – as parents of children with disabilities - are expected to know. We have to know the Mental Capacity Act, Deprivation of Liberty Assessments, Best Interests, Safeguarding, Intergrated Care Board Health Funded, 1.2 Rule Representative, Advocate, Court Protection, Disability Living Allowance indefinitely, Personal Independence Payment thresholds, all this shows that to navigate the system on behalf of someone with PMLD is a life of complicated form filing in, red tape and bureaucracy. There is no time for filling in these forms, all the forms that require the ticking of boxes. The boxes that are all negatively framed. Indeed, boxes that aren’t there that need to be ticked, boxes that aren’t appropriate. It is often a box ticking exercise that changes nothing.’

‘We often get asked by professionals how we are doing, feeling etc., so that they can put a tick in the box. Most of us feel trapped inside a box as the rest of the world rushes past us getting on with life. We are still stuck in the box struggling’.

(Mother, participant).

Feelings expressed by mother and father participants when given creative resources to take home.



TICK BOXES

☑

We often get asked by professinals how are we doing, feeling etc So they can put a tick in the box Most of us feel trapped inside a box as the rest of the world rushes pass us getting on with life. We are still stuck in the box struggling

Just some words on how we really feel and worries

Mother and father's thoughts on a tick box exercise.

One parent in a coffee morning stated that

‘No one asks how are you, how does this feel!’.

On reflecting this question, Becky offered her own thoughts:

‘There is no time when the form is about someone who is so complicated and complex. These systems are so complicated. How many other people in society must clamber through these systems? As parents we must jump through hoops, making sure they are the right hoops, fight for everything, fight for basic health care, go to court, employ people. We have to fight with the very people who should be helping us. We sometimes must find sums of money to pay solicitors to fight the very people and system who should be helping us. All of this is an added pressure for families who are already under pressure from having to care for someone with complex disabilities. Often, they are the expert in their care as syndromes and genetic problems can be rare. Sometimes there is no diagnosis. Sometimes the condition is a result of severe domestic violence or accident. These people are the most profoundly disabled on the planet.’

Parents described the inequality that they faced when navigating systems. Some parents reported hearing how other parents had to move to receive better care or facilities, as well as having to pay to receive better help. As one participant told us, if their adult child has to be in hospital, that itself becomes a 24/7 experience and it is exhausting for them. They must make sure everything is in place while also educating every member of staff who attends to their child. We heard of one parent who spent five months in hospital with her daughter. She supported her care and had to campaign for the right support at home in order to leave hospital.

The parents reported feeling powerless as decisions were made about their children, teenagers, adult children, not about what is in their best interests but how much money it costs. The parents talked about having photos of their children on reports would help with them being 'seen'. During discussion of their children's health and wellbeing, many family members in the group said that their loved ones with PMLD had a 'Do Not Resuscitate' (DNR) on medical forms, without consultation with themselves or parents.

'When they're children… you're the one that speaks for them and their best interests… the doctors will listen to you most of the time. But once they become adults it completely changes. You no longer are the person who represents their best interests, and they don't take any notice of you… And my son was in Intensive Care and they signed him off to be DNR without even a conversation with me about that.' (Mother, participant).

Each parent of a child who had an DNR on their forms reported that they got better. Parents also described how if their son or daughter was admitted to hospital, it meant a hospital stay for them too, as the medical team did not know the intricacies of care, even with a 'hospital passport'. Because of the parents' care expertise, they provided support for their children during hospital stays.

'I've been in a situation where my daughter went into care and the people that were supposed to keep her safe actually nearly killed her several times, and it wasn't until a manager came in and said, "We can't look after this person anymore", that I could get her out. I didn't have any power over her care at all. And I didn't know that when I put her into care.'

(Mother, participant).

Another example of when the system doesn't work is when C received a phone call. The job centre presumed C can hold a phone, understand what is being said, and respond. Parent takes the call, **'Why hasn't C got a job?'** The parent explained why their child does not have a job, to which the caller responded, **'Come to the job centre, please'**.
The parent then described struggling to take their adult son into the job centre to prove a point. They arrived at the reception of the job centre ready to take the interview, and the receptionist asked, **'Who sent you here?'**. The participant stated that **'The system did.'**

**'You just feel like they're on you, that they've got their eyes on you and you don't feel that they trust you. […] And every time a social worker comes over…
she goes through this nonsense every time, and I just say, "You're making me feel like you don't trust me".'**
(Mother, participant).

Once again, our participants discussed at length how no one asks, **'How are you? How does this make you feel?'**. They described how they wanted the system to change, in ways that truly reframed the way that people with profound and multiple learning difficulties, their parents, siblings, carers and allies are cared for. The parents reported having spent too much precious time trying to understand a system that doesn't work for them. The parents want to be asked **'How can we help?'** by professionals, and for professionals to listen, resulting in ways that the system can act on the best interests of their adult children and to support the family.

As this group realised at the end of the research, **'We are already creating the changes we want to see'**. The parents described how they are happy with the day care centre their adult children all attended. They described how they wanted the health and social care systems to catch up with them, rather than parents having to respond to these ineffective systems.

'We were so pleased that our day care staff asked what we wanted it to look like, rather than being told what it would look like' (Foster parent, participant).

The parents in our group knew that social workers were under pressure and get a 'bad rap'. These parents were empathetic to social workers because of their adult children: parents reported already being highly attuned, empathetic individuals, who have naturally developed this way because of the very people who they have looked after all their adult lives. The parents shared that some social workers have been very supportive, in terms of being asking the right questions, and making parents feel held and heard.

Despite such positive experiences, families did not always find their engagement with social services helpful. Families recalled a number of interactions with health staff that caused them distress. For example, a participant shared her upset when, talking about her daughter, a social worker told her she'd **'have to get her on the pill when she was a teenager and she went into respite'**, because she would be more vulnerable and that, **'she'd be bum-wipingly dependent into her teens'.**

This focus on intimate care, expressed in a way that lacks empathy and dignity, is stigmatising and reductive. It strips away personhood and focuses on the burden of her daughter's high support needs, reducing her to a bodily function. Although her daughter may have needed this level of intimate support, there were perhaps other, more sensitive ways of expressing it.

This type of insensitive approach was also reported coming from NHS consultants, with the same parent remembering how she was told: **'I can't tell you she's not going to die [but] you don't have to order the tombstone yet'**. Our participant reflected on the pain she felt on hearing these words through a poem:

'Your words were a punch I carried for years, a shadow in the cot, a lump in my throat every time she seized'.

Poem excerpt (Mother, participant). Full poem on following page.

“Don’t Buy the Tombstone Yet”

for the ones who doubted her, and the ones who never will

To the paediatrician,
when she was just three months old,
and I whispered through
trembling lips,
“I’m scared she’s going to die.”
You looked me dead in the eye -
“I can’t tell you she isn’t,” you said,
“but don’t buy the tombstone yet.”

Your words were a punch
I carried for years,
a shadow in the cot,
a lump in my throat every time
she seized.

To the neurologist,
when she was sixteen months,
you told me I’d never teach
her to drive.
“She’ll be bum-wipingly dependent,”
you said, clinical and cold,
as if dreams should be
extinguished early -
clean, efficient.

To the disability social worker,
on her first visit at three,
you spoke of pills and respite
and things that “happen.”
You meant to prepare me.
You didn’t mean to break me.
But you did,
for a while.

Those words lived rent-free
in the deepest part of me.
They scared me,
shaped me,
but never defined her.

Because here’s the thing:
She never learned to drive -
but she drove change.
She needs us for everything -
but she’s taught us more
than we could ever teach her.
She redefined strength,
not in milestones,
but in moments.
She is sass and sparkle,
fire and fight,
a soul wrapped in resilience.
She lit a flame in her brothers’ hearts,
taught them gentleness,
taught them what matters.
She changed me -
Mother, advocate,
woman forged in grief and glory,
leading the rare disease community
with a voice that quivers sometimes,
but never breaks.
And I used that adversity,
those scars and that strength,
to retrain as a social worker -
so I could be the voice I once
needed.
So I could stand guard,
not just for her,
but for all the others like her -
to protect, to listen,
to fight when needed.
You all tried to prepare me for limits -
but she gave me horizons.
So no, she didn’t become what you
predicted.
She became more.
And I?
I’m not scared anymore.

A poem created by a mother
when researchers gave participants
creative resources to take home.

> **‘People want support to have a life not a service’**
>
> Chair of ‘Think Local Act Personal’
> Clenton Farquarson

Theme of:

Time and the future

Parents spoke of the difficulty in finding the time to complete tasks outside of their ordinary routine. It is for this reason that we are particularly appreciative of the time they have given to our research:

‘Anything over our normal routines is a huge effort. This includes taking the time to attend these coffee morning research groups.’ (Mother, participant).

‘The length of our days are very short.’ (Mother, participant).

‘We haven’t got time for filling in 30 pages.’ (Mother, participant).

The parents described the increased time it takes for parenting, which has continued from babyhood into adulthood. As one parent said, **‘when Friday comes, so does our prison sentence’**, this was said because the weekends are often spent at home, indoors. The day service allows the parents to have some time for self-care or work. This father, grateful for the weekly attendance of his two adult children at the local day service is sharing how he has little time for himself or time with his wife.

Photograph of tree taken by father participant symbolising the rare moments for self-care.

Unfortunately, two adult children with PMLD died while our research was running. We would like to send our best wishes to their families and carers. From this experience of mortality, parents and the project team spoke of our collective realisation that time is of the essence and committed our resolution to get ‘it’ right for people with PMLD. As one care manager and father put so eloquently:

‘We are getting older; we want confidence in the future soon as to what happens next. And we haven’t got that confidence yet.’ (Father, participant).

Parents also spoke about how time given to ‘helping’ people with PMLD is instead being given to the wrong topic areas. Becky paraphrased a discussion between parents:

‘A child with disabilities often spends hours being taught how to interact with others… But why don’t we spend time teaching those without disabilities how to interact with them?’

Our participants described feeling immense love for adults with PMLD, whether that be parental love, sibling love or neighbourly love. This love was against a societal background of people with learning disabilities being devalued and disrespected. Participants were concerned that their children with PMLD were treated as second class citizens.

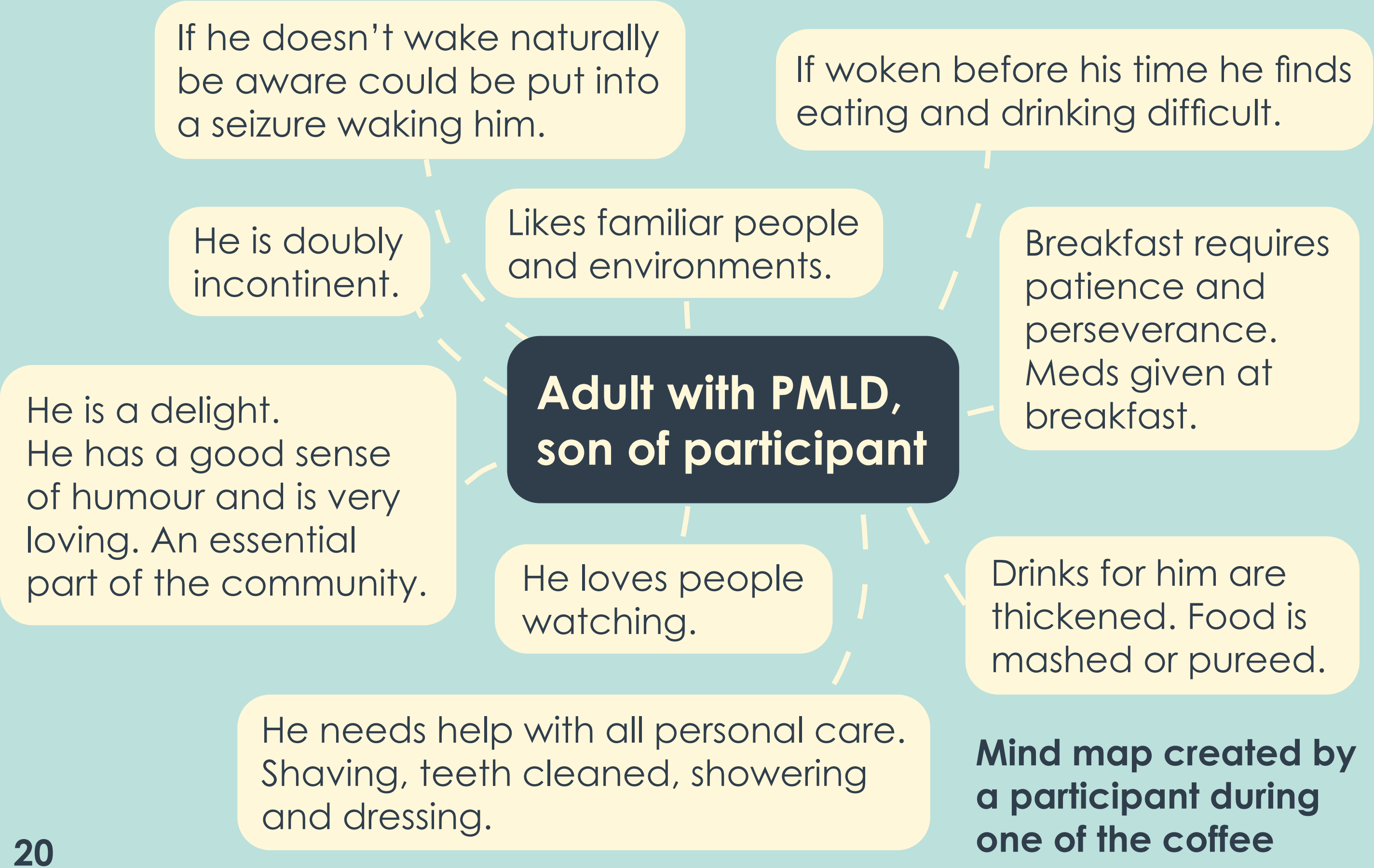
Participants were also concerned about the futures of their children with PMLD, particularly in terms of transition to older adulthood needs, and the support they may require.

Becky paraphrased a conversation that took place during a coffee morning about transition:

‘Turning 18 should be a joyful time. A celebration of leaving childhood and becoming an adult. For our families, they can celebrate the milestone, but nothing changes in their day-to-day caring for their adult child.’

This paraphrasing was echoed by a parent who described how,

‘We are reminded that if we weren’t here, they wouldn’t be here. We have given our lives to keeping our people alive.’ (Mother, participant).



Adult with PMLD, son of participant

If he doesn’t wake naturally be aware could be put into a seizure waking him.

If woken before his time he finds eating and drinking difficult.

He is doubly incontinent.

Likes familiar people and environments.

Breakfast requires patience and perseverance. Meds given at breakfast.

He is a delight. He has a good sense of humour and is very loving. An essential part of the community.

He loves people watching.

Drinks for him are thickened. Food is mashed or pureed.

He needs help with all personal care. Shaving, teeth cleaned, showering and dressing.

Mind map created by a participant during one of the coffee mornings.

Every parent felt the same and there was some small relief in that.
To start visioning for the future because what everyone wants for their adult children doesn’t exist.

One participant explained how he has

‘got a permanent knot in his stomach about the future for his son and that knot tightens as you get older’.

(Father, participant).

Parents are being asked by professionals what they need for their future, but this an unprecedented world where their children are living longer than expected. As a social worker said to one family,
‘Go and find what you want, then let me know’ regarding their future. But this a question that parents have difficulty answering. It is yet again a constant reinterpreting of the world and asking the very people who need support to do it themselves.

Parents described wanting conversations about the future lives of their children with PMLD. This included discussing person centred plans, transitions into older adulthood whereby there is a gentle holding and getting ready for a gentle letting go with the right carers and premises where their adult child will be most effectively supported. Parents wanted certainty that they as parents could look after themselves but also feel confident that their adult children would have a good life when they themselves die.

Parents were very aware that transitions need care, time and places created in order to work effectively. They again spoke of the need for a new model of care – a model of an enlightened future, similar to what they have at their day centre – where parents feel held, listened to, supported, trusted and at peace with where and who will look after their adult children when they have died.

Finally, this group of parents have found a daycentre that their adult children love to attend. Indeed, the very fact that this group of managers have joined us on this research journey tells us they are listening to the parents. We witnessed great supportive relationships between staff and parents. As our research concluded they were able to explore some of the future plans for the daycentre, which included how staff could take some of the burden off the parents’ need for quick outcomes.

The managers shared that they would consider putting PMLD terminology on their website, continue meeting up at different venues to continue the need for a supportive community that need to share, create informed guides, share the day care model as a vision for future respite and possible future community living. One parent has taken the role of continued research. This was an incredible unintended benefit of this research. This would allow the daycentre to informally carry on exploring the future for this group of parents. As one participant said,

‘We have a voice now’.

Theme of:

Empathy

Parents spoke of the need for empathy and compassion towards them and their children with PMLD, particularly from the perspective of professionals involved in their care. Participants were clear that training on empathy and compassion would be beneficial for staff. This training should be focused on the positive aspects of PMLD.

One participant described during a group conversation, which we paraphrased as the following

'Having a disabled child should not only be about listing what children *can't do* in order to gain understanding and professional support.'

Participants described how often, small moments of empathy (or lack of empathy) could have powerful consequences for them and their children:

'We do the things we can, rather than do the things we can't', one mother shared. **'The things we can do are very little, small things.'**

(Mother, participant).

A mother and father shared that although their son didn't want to go to college, his teachers insisted that college would be the best place for him. They said that he would be in the "community", and that **'other students would call and take him to the pub!'** The parents asked what has changed in three years – the teachers had said the same things when their daughter started college, and her experience was awful. Their son's social worker even visited and asked him three times. Each time, he replied with a resounding **'No!'** A participant in the group who worked as a care manager reflected that, **'he shouldn't have been asked more than once'**. (Mother and father, participants).

People reported **'feeling trapped'** and stuck in a **'prison sentence'** (Father, participant, see image below). This prison feeling was not due to being trapped by the family member – who is loved deeply – but by the system. Access to everyday life and experiences are hindered by language, physical barriers, and isolation. In other words, barriers and navigating system challenges were impacting and shaping the experience of empathy.

Feelings expressed by father participant when given creative resources to take home.

One father in the group said that he saw his son as

‘the solution. not the problem’.

The empathy that parents felt for their children made them feel a sense of obligation that they needed to advocate on their behalf, even if they were made to feel like *they* were the problem. One participant mother reported being considered ‘stressy’ by professionals.

Another parent said:

‘Well, that’s what you have to do. No one ever sends you a form that says, “Can you just send us a note back saying what’s wonderful about your son,” It doesn’t happen.’ (Mother, participant).

Parents described the need for an empathetic approach that is institutional, which is focused on listening in partnership, taking in account the best interests of the parents and adult children, but they acknowledged this experience was rare in reality. Because parents did not feel listened to, they felt a sense of mistrust towards professionals, particularly around concerns about professionals not understanding their child’s needs, their cues, eye movements, hand gestures, body language, sounds. Parents also wanted professionals to recognise and empathise that communication isn’t just about intellect or speech.

As a care manager explained,

‘And I think you just presume that they know everything. […] I think that’s the safest way’.

A token of thank you from researchers to participants acknowledging the little time they have to themselves.

Conclusion

We needed to collect the lived experiences and social histories in a way that was supportive and caring, in ways that didn't put on extra strain on parents' already busy lives. We wanted to hear from the very people this research is about (adults with PMLD), but the ethical considerations to do this would have taken the length of this project and beyond. We urge all academics, professionals and policy makers working in this field to consider ways of hearing directly from adults with PMLD, so that future research includes their voices more fully, and represents their needs.

A limitation of this research is that we could have visited more families at the other centres across Somerset where their relatives were spending the day. Unfortunately, time and budget didn't allow for this. Our four months of collecting stories seems too short, but even this time gave the project rich and wonderful stories. The parents felt that creating films about their stories that are short and to the point will help get their urgent messages across. Our hope is that these films will have power, and that they communicate to everyone's heart that a life well lived is for everybody. People with a lived experience of PMLD bring a nuanced understanding which is rare and hard to demonstrate in books or film, but we hope that this group of parents felt heard and that we were working together as active contributors to the story. We want the themes represented in this research to become part of their history, not constantly repeated and experienced. These films will be shared as widely as possible, and we hope that they take on a life of their own. We will share these films, so they become a resource for anyone working directly with people with PMLD. Now it is time for their stories to take centre stage. At the very heart is a simple but powerful call: let's get 'it' right for our family and friends with profound and multiple learning difficulties, for then true inclusion begins.

A packet of seeds given to participants by the researchers to symbolise the 'seeds of thought' they had all planted.

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https://www.bathspa.ac.uk/projects/we-are-the-people/