

I Can if You Can –

Our PAMIS Digital Passport



Meaningful engagement - What is it?



The world Health Organisation defines meaningful engagement as:

"the respectful, dignified and equitable inclusion of individuals with lived experience in a range of processes and activities within an enabling environment where power is transferred to people; valuing lived experience as a form of expertise and applying it to improve health outcomes".

For engagement to be effective it is important to present a clear purpose and intention, adopt an inclusive approach that defines the purpose of the engagement and what subsequent actions will be undertaken. Too often there is no follow up. Feedback to the participants is crucial.

This resource has been developed to provide background information about the lives of people with profound learning and multiple disabilities (PMLD). If meaningful consultation and engagement is to take place with this group it is crucial that there is an understanding of their lives, otherwise misunderstandings and misconceptions may misinform the engagement process. The lives of this group of people are very complex. It can be daunting for anyone undertaking engagement to enter into a dialogue/conversation about what may be very difficult topics and that might unintentionally impact negatively/promote trauma responses on both the person being engaged with and those undertaking the engagement.

Stories have and continue to be central to the work of PAMIS and this resource contains stories that will help inform a consultation/engagement process by providing an insight into the lives of people with PMLD.



I Can engage with you If – You Can listen and hear my story



Story has always been central to the work of PAMIS and this resource celebrates this. It does not capture or describe every aspect of people's individual stories, it does provide an insight, a glimpse, into some of the lives of people with PMLD and will support a better understanding in order to more meaningfully engage. Through these stories some of the challenges and barriers that are faced are recorded alongside some of the highlights. It shares the many different ways that people with PMLD can engage but this does take time, familiarity, understanding, patience and trust. It will support the journey of engagement.

Profound means deep, wise, expert – embark on this journey with the best educators we have, those with profound learning and multiple disabilities

This resource is a living document and will constantly evolve over time. The passport is easily navigated, just click on the relevant bubble on the contents page to skip to the section you require.

Further information on the PAMIS story consultation tool will be added to the resource in due course.



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I Can



*“I **Can** is a challenge for us all to use our imagination, expertise, influence, and passion to ensure that children and young people with profound learning and multiple disabilities and their siblings have the same access to a safe, healthy and happy childhood as other children do. Let’s listen to them with all our senses and support their dreams.”*

Jenny Miller – CEO PAMIS

The themes in this document are taken from the PAMIS presentation ***I Can if You Can*** and have been identified by families as areas that are important to discuss in terms of enabling children and young people to live their best possible life. Each theme is a snapshot of the topic discussed. They highlight barriers and challenges that this group of people and their families have to overcome in order to access their right to a safe, healthy and happy childhood.

The sections in the story toolkit are the inspirers of change. Stories can influence change by enabling the individual to change their own narrative. They can support communities in their understanding of the people living within it. They can enable those working with people with PMLD and their families to better understand the aspirations and needs of the people they are supporting. Storytelling and narrative helps support all of us with our physical and emotional well-being, and it can be fun!



Acknowledgements



We would like to acknowledge the children and young people who have told their stories in this document and to the families who have supported them to do so. Thanks to Pat Graham, family carer and the Chair of the PAMIS board for the *I Can if You Can* and to everyone else who were willing to share stories from the journey of their lives. These contributions are valued and appreciated and will help the Scottish Government and local communities to shape policy and practice to enable children, young people and adults with PMLD to live their best lives in communities that welcome, value and include everyone.



Thanks also to Alexandra Strick and Steve Antony for their inspiring picture book ***You Can***. And The Edinburgh International Book Festival for providing a platform for people with PMLD to engage with the book and tell their own stories of what they can achieve if people only listen. Thank you to all who came together to undertake this work. Your involvement has amplified the voices of children and young people with PMLD.

Note



This is a snapshot of some of the important themes that are relevant to people with PMLD and their families, it is by no means comprehensive due to time constraints.

The story and narrative toolkit section is a brief overview of some of the tools a story practitioner might want to utilise. It should be highlighted that each of the methods mentioned are models of practice in their own right and should not be attempted by anyone who is not trained in their use. The PAMIS story practitioners are highly skilled in story and narrative work as well as family support. They are sensitive to and have experience of supporting the trauma and emotion that might surface as a result of retelling stories in both story listener and story teller.

Working with story is powerful, effective and life changing. People and families need time and support to tell their stories.



thanks to 742680 for use of image



Introduction



Stories for Understanding and Engagement



People with PMLD and their families are some of the most excluded within our communities, and currently some of the most isolated.

A person with PMLD has a profound learning disability, most will have a life limiting condition and be non-verbal; a wheelchair user; doubly incontinent; hearing and visually impaired; epileptic; gastrostomy fed and have respiratory problems requiring suctioning and oxygen.

Having a profound learning disability means that someone's understanding, and experience of the world is life-altering and different to those who either have a mild or moderate learning disability, or those who do not have a learning disability at all.

Caring for a person with PMLD is an intensive and isolating role; many family carers provide this 24/7 with little, if any, respite.



Stories for Understanding and Engagement



However, PAMIS recognises that profound means deep wise and expert. This group of people never cease to amaze us with their contributions and insights. PAMIS ensures that they and their families are recognised and valued for this. Their role in education of communities and practitioners in how to care, how to act with compassion, how to communicate, how to be solution focussed and importantly how to work together is essential if we are to develop inclusive communities.



Only when we bring together the expertise and knowledge of a whole team including the person with PMLD and their family carers do we begin to understand the needs of this marginalised group of people and develop ways to ensure they realise their dreams and potential.



People with PMLD are our best educators and all they ask is to have the opportunity to be valued for who they are, supported to live their best life and have the same opportunities in life as everyone else.



The resource - I Can if You Can



Through providing insights into the stories of their lives the people with PMLD and their families make a valuable contribution to develop our understanding of how to meaningful engage with them.

The PAMIS Digital Passport

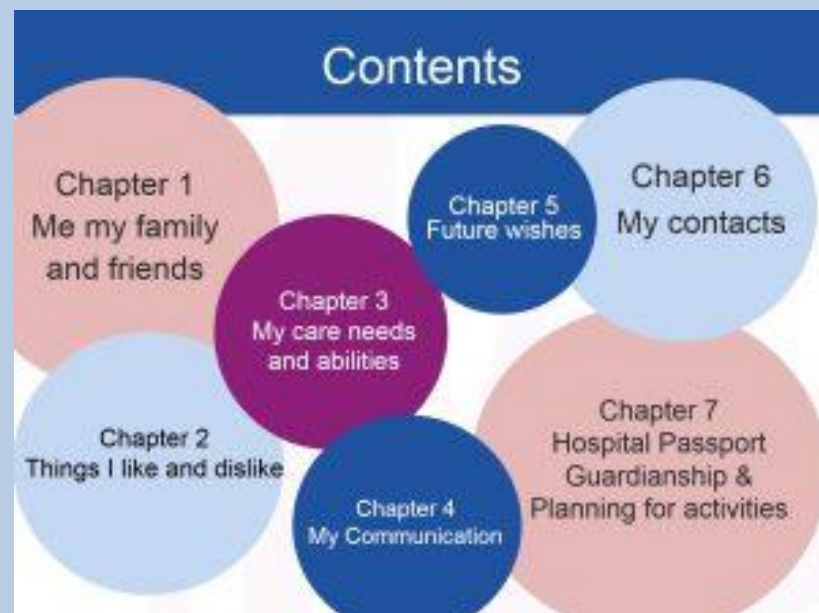


The PAMIS Digital Passport was developed by people with profound learning and multiple disabilities and their family carers.

Uniquely, the passport, and the information contained within the passport belongs to the person.

Development of the passport is led by the person with PMLD, and supported by their family carers and/or the practitioners supporting the person.

The PAMIS Digital Passport uses video, photographs and description to provide a platform for people with PMLD to express themselves unambiguously and in the way that suits their chosen communication best.



The use of digital story-

sharing and self-advocacy



Because people with PMLD are excluded from most of the ways that their peers use to maintain their relationships and express themselves- social media, blogging, online gaming etc, children and young people with PMLD are one of the most digitally isolated groups ever, and their contribution to the society around them is fragile, easily lost and depends on the actions of others

For PAMIS, and for people who have PMLD, and for those beyond that who need support for communication, the free PAMIS Digital Passport offers a truly person centred, citizen owned way that people with PMLD can show what their lives are like and what support they need.

By using a mix of story, personal narrative and a sensitive approach using film and photography, and then conveying this within a resource that was developed by people with PMLD- The PAMIS Digital Passport helps us to make steps towards acknowledging the lives of those children and young people that live with a profound and multiple learning disability- small steps for us, important and necessary for them.



Hidden Voices



Living at the edges of a spectrum has its own risks. Those who have a very mild learning disability may be able to articulate their lives, needs and experiences well, and might find some of the adjustments put in place for those who have a greater learning disability patronising and un-necessary.

Conversely, those who have a profound learning disability can find reasonable adjustments that are in place for “everyone who has a learning disability” excluding, unsuitable and just not enough.

Their voices are drowned by those who are louder and more able and there is a risk that those in positions of influence will miss the voices of the quietest.

This is where adjusting how we listen and respond to people who have profound learning disabilities is vital. At PAMIS we advocate the use of multiple different ways of supporting people with PMLD to show their lives, their hopes, their dreams, their promise. We support them to lead on the 24-hour care that supports them and own their experiences so that their lives are valued by others.



And people listen

To teach others that they are not “hard to reach” and can advocate for themselves give consent and show you what they need if people listen more appropriately.



Future Wishes

Please
Learn my
language!

I want to go to
Uni and be a
student like
everyone else.

I want to go on
holiday with my
family to the
countryside.

I love Metal and
go to Bloodstock
every year with
my brother!

I have my
own
business dog
walking!

Don't assume
that my
therapeutic
activities are my
life's ambitions-

Give me the
chance to have a
legacy too.....



www.pamis.org.uk

But it goes way beyond health and social care needs...

How are Digital Passports being used?

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Shows people what I can do,
and how I like things done

My sister put photos of her at
Uni on it.

It's how my brother's
girlfriend got to know
me 😊

Helps people learn how to see
me! As a friend, a sister, a
brother, an individual

Has videos of my gran telling
me stories before she died

Lets me express my own
excellent musical tastes

It's a repository for my
memories and photos

Contains cute videos of
my dog and hens :D

I have my Picture
Symbols and my
Talking mat on it

Helps people include
me in decisions

Helps me to share my own
personal information just like
you.

Everyone from church
put their picture on my
passport autograph page

It's my cultural
history

Helps me to contribute to
consultations and take part in
research

How many sugars do I
take in my tea??

Contains my Christmas
card list!

Playlist 4
Life 😊

Helped me grieve for
my Grandad



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From a place of understanding



All aspects of health care are affected by how communication and listening takes place and is interpreted. Truly understanding what the person with PMLD is saying needs time and effort on the part of those seeking to understand.

Often we can only do that if there is a bridge; a way to show, for example, what oral health care is to someone who can only communicate with their smile, how effective body shape protection and positioning can mean the difference between someone sitting at the dinner table with their friends and peers at school, or “being fed” in their wheelchair in the corner of a room alone.



Every picture tells a story



We use video, photographs, and stories to separate the layers and show unfamiliar carers and support staff how to meet someone's needs in an unambiguous way.

We use pictures to illustrate what their body positioning should be and we use multiple approaches to show how staff can support people's complex care, particularly during key transitions. The use of story allows the narration to be truly person centred and helps to remove barriers and grow compassion, empathy and understanding.



Everyone needs support at some time to help them advocate for their own needs and children and young people with PMLD are no different.



Health and Wellbeing



When we think of the health and well-being of people with PMLD, who do we see here? Do we see someone with a disability and rush in to do what we can to alleviate things for the person, or do we see a person with ability and listen to their voice of experience guiding us to support them? It can be obvious, or it can be subtle.

At first glance, everyone with PMLD will need considerable support and the majority will need support 24/7 for their entire lives. This is because not only do this group of people live with their complex disabilities, but they also live with other conditions that are serious in their own right, for example epilepsy, mental health challenges, mobility constrictions, sensory impairments and chronic respiratory disease.

Many will have lived through supportive, though serious surgeries to implant gastrostomies, or spinal rods, or shunts.

The instances of related trauma is high and the opportunity to have appropriate psychological support and counselling for this is non-existent.

Therapeutic interventions, if we are not careful, drive their entire life and within the stories, we see what is important for the person apart from therapeutic work.

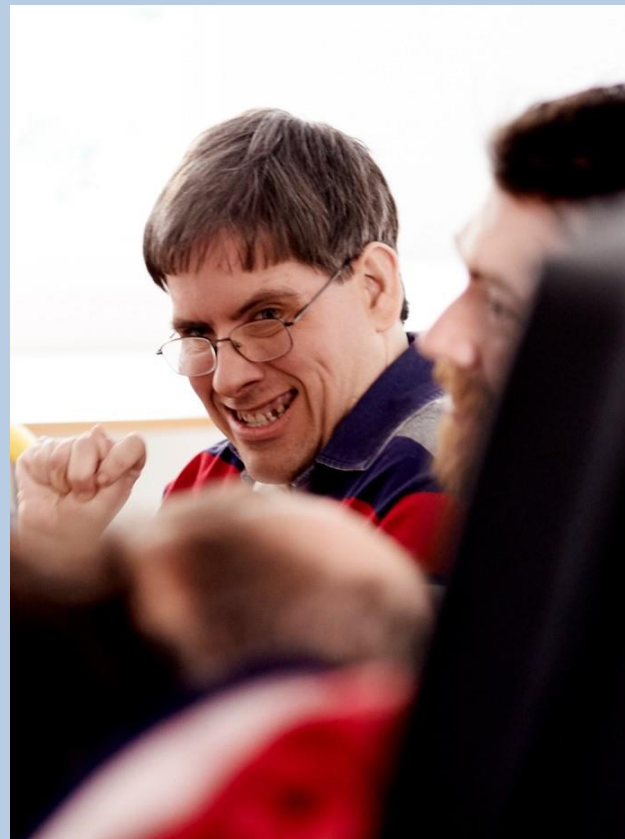


Avoidable Deaths



It goes without saying that because of their complex health conditions, these children and young people will have shorter lives, and many will live and die without having the opportunity to make their personalities visible beyond their disability.

Research on the deaths of people who have a learning disability show us that many will die of avoidable causes, often because staff do not know or understand that illness can present very differently when someone has a profound learning disability, and supporting a young person with PMLD to advocate for their own health and care using methods that are appropriate to them is vital.



The Importance of Protection of Body Shape and Postural Care



People living with profound learning and multiple disabilities are at risk of deteriorating body shape which can lead to problems such as restricted function, skin breakdown, pain, eating, drinking, swallowing, and breathing. The problems can be so detrimental to individuals that they require surgical intervention or can contribute to avoidable and premature death.

However, posture and positioning can be managed 24 hours a day, 7 days a week to support the maintenance or improvement of body shape. This process of supportive posture and positioning is often referred to as postural care and, after information and education, can be implemented by anyone involved in the person with PMLD's life. Postural care can stop, slow down or reduce some of the issues mentioned above, enabling the best functional movement possible including head support making it easier to communicate and take part, minimizing skin breakdown as pressure is better managed, reduce pain as muscles are no longer being pulled, strained or stretched in an uncomfortable way, where possible a safe swallow can be managed making eating, drinking and swallowing more tolerable leading to less chance of aspiration and respiratory function can be managed in a way that enables the best lung function possible.



People with PMLD use their Passport in pioneering ways

To maintain their independence and lead on describing their own complex care needs in an accessible way.



Links

Your Posture Matter Turas Learn page, this is the national One Stop page for postural care in Scotland: [Your Posture Matters](#) | [Turas](#) | [Learn \(nhs.scot\)](#)

[Rates, causes and predictors of all-cause and avoidable mortality in 163 686 children and young people with and without intellectual disabilities: a record linkage national cohort study](#) | [BMJ Open](#)

[SLDO film: Reducing child deaths from chest infections](#) | [Publications](#) | [Scottish Learning Disabilities Observatory](#)

Sharing Postural Care stories



Postural care is lifelong, life enhancing and possibly life extending in some cases. Therefore, the ability to share their own postural care story could be incredibly powerful for someone living with PMLD. This can be a way of helping the people supporting someone with PMLD not only understand the reason why they are following a postural care plan from a protective perspective, but also the function, ability and opportunity that is being created.

Postural Care for Sitting



Ensure bottom is positioned well back in chair and pelvic strap secured firmly where present. Ensure feet are supported and head and trunk positioned and supported in an upright, midline position where possible.

Unsupported Position

Supported Position

Postural Care for Lying



Unsupported Position

Supported Position

Ensure head, trunk, pelvis and legs are positioned centrally and symmetrically aligned where possible. Ensure head and extended knees are supported by a pillow or other system.

Postural Care and Management



Postural care is not intuitive!

Simple Stuff Works tells us that:

"Postural Care is the gentle, respectful, consistent and effective means of protecting body shape"

Postural care impacts on:

- breathing
- eating and drinking
- pain
- communication, behaviour & relationships
- overall, quality of life

[Tap here to watch an Introduction to Postural Care](#)



What further outcomes are needed to ensure people with PMLD to access digital to have their voices heard?



Currently there are pockets of work being undertaken about the use of digital on the lives of people with learning disabilities but these do not tend to include those with PMLD as it is assumed they cannot use technology.

The PAMIS Digital Passport has been recognised as a gold-standard resource to help children and young people to overcome this exclusion, however for this to be as effective as it can be the, children and young people need to take the lead and show the world what they can achieve and what better way to do this than through video, pictures and stories.

The attitudes of those supporting the child or young person are very important and it is crucial that people are aware just how much the passport can help them understand the lives of people with PMLD.

The PAMIS Digital Passport is a living document that grows with the child but if aspects of their lives are captured in the passport then it becomes their personal life history. The passport gives them the ability to show the world who they are, what they love and how they communicate. It offers endless opportunities from capturing life stories, family histories and anecdotal tales of important life events. It gives them a voice but is up to those that support the child or young person to make this a reality by not only creating a passport but by using it once it is created.



Inclusion

Inclusion requires an understanding of what and how an individual wants to be included. It will mean different things to each individual and it will change over time.

For evidence of good practice - The National Galleries of Scotland, (Modern 1) has developed an inclusive model. They considered the physical space, listened and learnt from families and other organisations and then considered the story space. They link everything to their collections and installations, so they are meaningfully including people with PMLD that visit.

This is inclusion in a public space for those that can and want to attend. They constantly reflect on their events and the family events contain something for everyone.



Families want to make memories together and why shouldn't they? The rest of society have opportunities to make memories together doing things they love to do and it is no different for people with PMLD and their families. From festivals, to museums and art galleries. From culture to heritage and sport families just want to make memories while they can.



Me



This Is ME

My name is Prunella and I love adventures. Here are some of my adventures.
In my community I attend guides and go to guide camp.
I love going on holiday and doing new things.



Inclusion

Some of Prunella's Adventures.

Prunella loves to have the same opportunities as you or I. Inclusion for Prunella is being able to try new things and participate in her own way in an accessible physical and social environment.



Inclusion

Prunella's Adventures.

I can only access the festival because the PAMILOO is there.

I can only go to the National Gallery of Scotland and take part in fabulous opportunities because there is a Changing Places Toilet and people there who make sure the activities are accessible to me.



Inclusion

I WANT PEOPLE TO WORK TOGETHER TO ENSURE I CAN ALWAYS HAVE FUN AND TAKE PART IN EXCITING ACTIVITIES AND EVENTS BOTH AT HOME AND ON WEEKENDS AND HOLIDAYS

See the link below to view our work.

For more about the exhibition please click on the link <https://app.smartify.org/groups/your-art-world-t9bso>



What further outcomes are needed to ensure people with PMLD are included?



There will be some people who cannot attend events and offering outreach would provide possibilities for purposeful and meaningful activities and contribute significantly to lifelong learning.

This could be embedded in communities supporting the outcomes in The Cultural Strategy for Scotland.



Inclusion – requires access.



I can go to the loo

Scottish Gallery of
Modern Art, Edinburgh



Blair Drummond Safari Park, by Stirling



Rothies Halls, Glenrothes

Lochore Meadows, Fife



Burrell
Collection,
Glasgow



Access for people with PMLD means they should be able to access the physical environment easily and know that they can go out for a day just the same as everyone else.

PAMIS has been weaving together accessible, inclusive, and creative communities that offer increased opportunities for people with PMLD to enjoy book festivals, music festivals, nature festivals, children's festivals, art galleries, museums, heritage, folklore.

To enable this we have worked with communities to support them with physical access in terms of ensuring they have Changing Places toilets in their buildings or they hire the PAMIS mobile Changing Places toilet the PAMILOO, to ensure people with PMLD can be a part of their communities.

The latest PAMIS Changing Places report highlights where people would like to see Changing Places in the future.

Changing Places Toilets



4. Places people would like to see CPTs provided...

1. Country parks / open spaces
2. Tourist attractions
3. Transport networks
4. Entertainment venues
5. Retail



	%	n
Country parks / open spaces / seaside	63.3%	762
Tourist attractions	59.9%	721
Transport networks	58.3%	702
Entertainment	53.4%	643
Retail	52.6%	633
Hospitality	50.8%	612
Healthcare buildings	48.9%	589
Leisure / sport venues	48.4%	583
Public buildings / libraries / places of worship	45.7%	550
Other	7.3%	88

The table is based on an overall sample of 1,204 (includes fully and partially completed responses).

The second highest number of registrations in 2022 was in the arts/museums/library (21.43%). 2 facilities were registered at the Burrell Collection in Glasgow and 1 at Centre Stage in Kilmarnock, a performing arts centre.

This information indicates that people with PMLD and their families want to access their communities the same as everyone else.

Building legislation is supporting this access but more awareness is still needed so that communities understand that changing places toilets really do change lives





Purposeful and Meaningful Activities



People with PMLD require support to engage in activities that provide meaning and structure to their lives. Understanding what this might look like for the individual requires time and a deep understanding of the person.

Repetition of the activity enables those working with the person to make an assessment of whether the activity is being enjoyed or not. It provides time and space to explore an unfamiliar environment or activity.

As with all of us when participating in new activities, we require a range of information and support to take part. Before we can make a decision, as to whether we want to carry on, we require to have time to process the experience and for a person with PMLD this is no different, except it takes a lot longer.

I can be a sportsperson



I can help others too



Purposeful and Meaningful Activities



Purposeful and meaningful activities for people with PMLD, as for all of us is unique and individualised. We need to spend time with people who know and understand the individual to ensure we provide a range of activities that are right for the person. One size does not fit all and for many the activities that should be available are ones that we all take for granted.

Accessible and inclusive activities need to be planned for all. If we consider the needs of those with the most complex needs we will get it right for everybody.

Accessing practitioners such as Occupational Therapists will support the right adaptations to be made to activities so they are accessible. They will also provide ideas about how everyday activities like cooking, baking, washing, gardening can also provide structure and meaning.

Purposeful and meaningful activities support improved health and well-being and a sense of achievement for people with PMLD as well as offering lifelong learning opportunities.

I can take part



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I can cook



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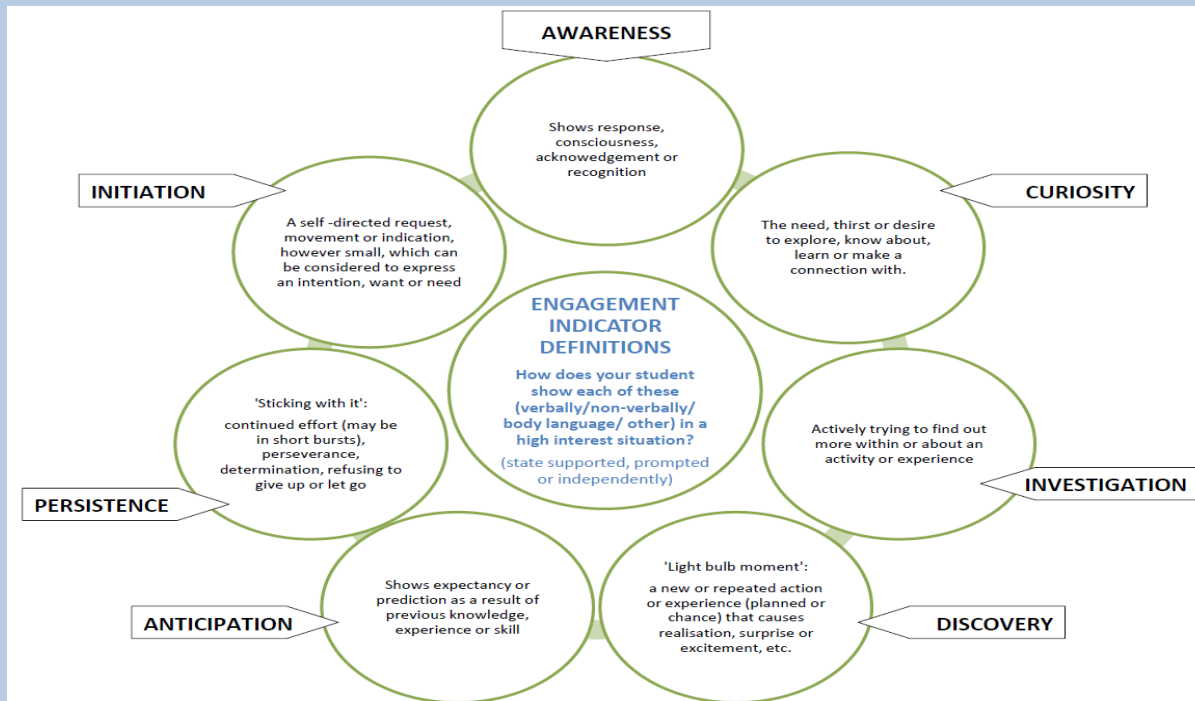
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Purposeful and meaningful activities



The breadth of activities that we all have the options to try out should also be on offer to people with PMLD. We just need to recognise how someone is choosing their preferred activity and provide opportunities to try out new things. Drama, art, dance, music, and storytelling, skiing, surfing, boating, riding, cycling – with adaptations and imagination so much can be on offer.

The positive impact of exercise, movement and activity is well documented and is as beneficial to people with PMLD as it is for everyone else



Me



This Is Me

I love stories, music, chocolate cake and spending time with my family and friends. I love swimming with my friends. I live in Kirriemuir with my mum, my brother Taylor and my sister Pyper Rose.



More about me



My name is Leo Bruce Davidson

I was born on 22/09/2014

I have Infantile Neuroaxonal Dystrophy, I am nonverbal and I use my wheelchair

My conditions affects my life in many ways and I require support with my personal care, dressing, eating and drinking as well as accessing my local community and enjoying purposeful and meaningful activities in my community.

My physical and emotional well-being are important and necessary, to keep me well but that doesn't define me.

I am a very sociable boy and love being around others. I love playing with my friends.



Health and Well-being



When I was 18 months old my mum saw a change in me and took me to the doctors. My mum went back and forward 6 times trying to find out answers. I was two and a half years old when I was finally seen as an outpatient at hospital. Then I had to wait a year and half for funding for genetic testing. My mum was then told I had Infantile Neuroaxonal Dystrophy. This affects my nervous system and eventually I will have difficulty moving.

I have problems moving independently and breathing properly. I am prone to infections like such as pneumonia.

- ***It is important to know about my medical condition and that I will slowly deteriorate over time. This can include loss of sight.***

I need help with all my personal care, with dressing and undressing, well as all my exercises for my legs, hands and arms.

I love the hydrotherapy pool because I can go swimming with my friends.



Equipment I need



Standing Frame

- I used to have a Leckey horizon standing frame. I got hoisted into this supine then the standing frame was tilted into an upright position that was right for me.

I don't do this now as I am not as strong as I was a few years ago.



Splints

- These have been provided by the Orthotics Service who should be contacted if there are any issues.

AFO's

- I have Ankle-Foot Orthosis' that I wear daily to keep my feet in a good position.



Resting Hand Splints

- These help stretch out my hands and are used at home



Communication



I can:

- Recognise familiar objects, photos and pictures
- Point to things that are near to me with my fingers and hand. I use my vocalisations and facial expression to communicate. I use some gestures and signs to tell you things.
- Point to pictures in my communication book to tell you what I want

This was what I used to do to interact but I can't really do this now because I am not strong enough to press my switch any more.

Storytelling over time:

- Someone would place the voice output switch on my tray or table where I could reach it during a story or song. The switch would stay there until the end of the activity - that helped me to learn how to use it at the correct time. I might have pressed it lots of times during the story but I was still learning when to press it and it was very exciting. When it came time for me to "say" my line, the person supporting me would pause and give me time to press the switch. They gave me lots of praise when I got it right and they ignored me when I pressed the switch at different times. I can't do this any more but I still love stories.

Big Mack Switches



This simple communicator has lots of uses! It's easy to record speech, music or any sound into the **BIGmack**.

Record a repeated phrase from a story or song for me to play back at the right time.

I loved doing this but I'm not so able to do it now.



Health and Well-being & ME!



I JUST WANT TO GO SWIMMING WITH MY FRIENDS.

You talk of posture, of stretches and risk
They're important - I know
So I sit and I wait, and I wait and I wait
And you talk and you talk and you talk
I listen, I watch and I wait till you decide what's best for me
I catch my breathe as I watch and I wait
Will they decide to let me swim?
I really hope they do
I want them to see what it means to me
Why don't they understand?
In the water I am free
I want to scream and shout
I am me!
All I want is for you to understand
I JUST WANT TO GO SWIMMING WITH MY FRIENDS
I'm Leo Bruce Davidson
I AM ME!



Important to ME - Milestones and events where support is required.



Birth to nursery – support for new mums following the birth of a child with PMLD is something that is necessary but not always readily available to many. An understanding of chronic sorrow and the impact on the family is easily overlooked at these times and subsequent milestones in a child's life means this is experienced multiple times but the impact is not necessarily always considered.

Nursery to school – Again this is another often overlooked area where sensitive support for everyone may be necessary. It is quite a transition and the issue of trusting people with the care of a child with PMLD starts to emerge for family carers.

Nursery to Primary then Secondary school - Again further transitions and milestones where consideration might be given to the provision of emotional support as well as practical support.

Leaving school to begin the journey to adult services -This journey is a difficult one for families, as life as they knew it ends and a very new journey begins. It is a journey filled with uncertainty and the unknown. All the familiar routine of education finishes and the emotional impact of the uncertainty and the unknown is one that is very difficult for people with PMLD and their families.



Education and Lifelong Learning



I can learn

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Education



Children with PMLD deserve an education appropriate to their needs. They deserve a curriculum that considers them for the wonderful children and young people they are. One that caters for them as individuals and provides a nourishing and creative environment that meets their needs.

Currently whether that is available in education very much depends on your geographical area and the current policies adopted in that area.

Very often successful education of children and young people with PMLD is down to an individual head in a school. Families also feel that more training should be provided within teacher training at university



Education-A Mother's Story.



"WHAT OUR CHILDREN NEED MORE THAN ANYTHING IS COMPASSION, COLLABORATION AND A WILLINGNESS TO LISTEN TO BOTH THEM AND THEIR PARENTS".

Listen to Silj's Story:

How Can My children have a perfect life?



Education-Alex's Story



Alex's wish: "I want school to better understand that unlike a toy, my batteries can't be replaced. I'm giving my all, I just need more rest than you".

Silj's son Alex feels exhausted just getting organised for school and he wanted to tell the story of what that is like for him, in the form of his favourite kind of book, A Flap Book. We hope you enjoy his story.



Transitions



Life Transitions

We all have dreams and aspirations in life and we journey along life's path navigating these transitional periods as best we can. For people with PMLD and their families, the emotional impact of chronic sorrow is something that many experience at every milestone and transitional event that happens in a child's life. The constant reminders are always present and the continual losses may create a cyclical sadness over time with no predictable end. Feelings of loss, fear, disappointment, guilt, may be experienced alongside the joy and understanding that someone with PMLD brings to life.

Siblings too may go through their own journey with chronic sorrow as might the person with PMLD.

Leaving school is one of those life transitions that is scary but exciting too. To be moving on along towards the next step of the journey has its challenges for any young person and part of alleviating any stress for them is to have a robust planning system in place to help them navigate their way through this transition process.

Mary's story demonstrates the emotional impact and worry placed on someone with PMLD and their family when this planning is not as robust as it could be.





My name is Mary and I live with my parents and my two younger siblings. I attend school five days a week. I go to school on the school bus. I leave school on 31st May 2023,. My family are worried as my social worker from the children and families team has just left her job and there is no one to take her place.

I have profound and complex disabilities and require 1:1 support to participate in activities and access my local community. I need 2:1 support for all my personal care and support needs. Due to the complex health care support needs and the fragility of my bones I require staff to be trained and also to ensure any risk to my health and well-being is minimised.

This is how I am often described

Mary has:

- Cerebral palsy (GMFCS level 5)
- Respiratory issues (suctioning currently being explored/training being provided to mum)
- Focal Epilepsy (emergency medication is NOT required but daily medication is administered)
- Cerebral Visual impairment – (Mary is registered blind)
- Complex learning disability
- Bone fragility
- Gastrostomy tube fed. (all medication and fluid given via tube)

This is Me



- I like busy/ noisy places.
- I like loud noises e.g. Kids playing, people talking or music.
- I like being with my family and being included in conversations about what is going on around me.
- I enjoy sensory tactile activities , massages, hugs and kisses.



This is Me



- I love the outdoors
- I enjoy listening to stories and sensory activities help me engage with the world around me
- Body signing helps me to understand what is happening around me as I am registered blind
- I love my family, my friends and engaging with life through conversation, sound, touch, smell and cuddles.



Transitions

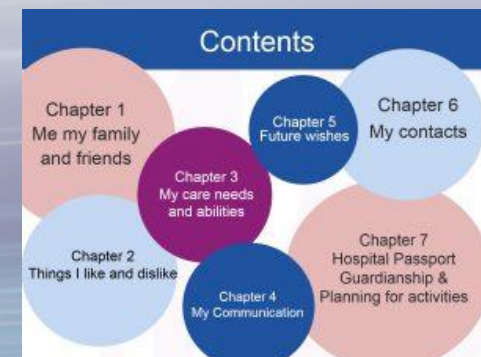


With only 12 weeks remaining of the school year Mary and her family were nervous as an adult social worker had not yet been allocated, therefore an adult Self Directed Support budget has not been agreed, and no building base day services or home care support services had been secured.

At the moment there seems to be issues with accessing all social care services. They are either at capacity or are unable to secure additional staffing ratios to enable them to support packages of care support.

The family are receiving transition support from PAMIS – to date a parent carer response for the Special Needs Assistant scheme has been completed, a PAMIS digital communication passport has been developed to support transition. Service visits have been scheduled for the family and links have been established with CHAS and education.

Mary currently receives home support from Barnardo's Apna Care, to support her mum with showering, personal care, and bedtime routine. Mary is also linked into CHAS where she accesses overnight hospice support, however, Mary is also on the transition pathway from this service into adult hospice support. Bearing in mind that this is another change in Mary's life that she will have to cope with alongside leaving school. The support from adult hospice care will be very different from the planned overnight hospice support Mary and the family currently receive from CHAS.



[illegible]

Planning for Independent Living



“Planning for independent living, including appropriate housing choices and living environments is another huge leap into the unknown with so many hurdles to jump and so many systems to navigate. There is so much to consider when planning for independent living. Currently families feel afraid for the future and are lost in a sea of despair to be honest. The gap here between policy and practice is wide. There is so much that requires to be done in this area it is difficult to know where to begin.”

Currently there is little in the way of considering the community that a person would be best placed in and how accessible that community is for someone with PMLD. There is also little consideration in most instances of whether the residents living together are compatible with each other. Helping people to live independently should be part of everyone’s long term future plans. It is everyone’s right to live in a safe community in accommodation that suits their needs and in an environment that helps them to grow and develop and live the best life possible.



Stepping Stones-



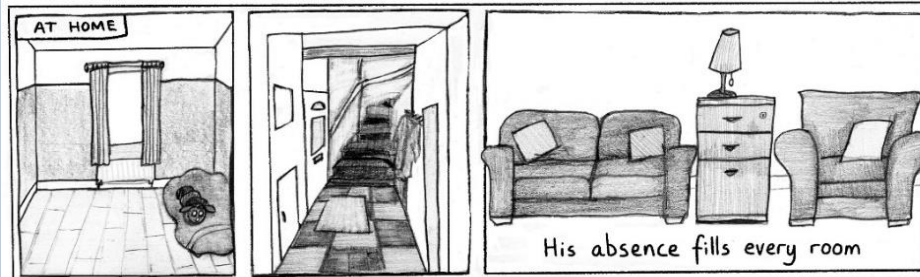
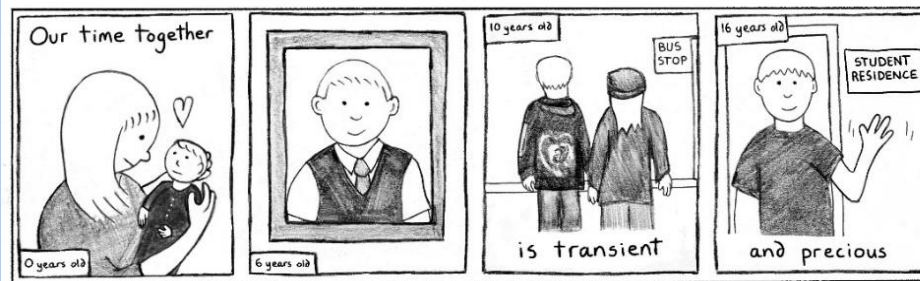
Stepping Stones is a story that captures the emotions of transitions. Thanks to family carer Kathleen Shearer for sharing the family story. (Written and illustrated by Kathleen Shearer)



Stepping Stones

My son was born autistic with learning disabilities and diagnosed aged four. He is now sixteen and resident at a school for young people with autism. It took two years to find a suitable placement. In another two years he will transition to adult services where every aspect of his life looks uncertain. Why should this be? It's no surprise that the child diagnosed twelve years ago will soon be an eighteen year old man with complex support needs. Yet I already know that getting him the help he needs will be a struggle.

My comic aims to show a snapshot of the emotional journey for families. The title "Stepping Stones" relates to my own childhood and memories of crossing a local burn. The stones were slippery but one was safer than the rest and I was often reluctant to move on to the next one. I was reminded of this after an enjoyable visit to see my son and feeling reassured he was settling in well. But this is only a temporary place of safety and we shall have to move on. The real challenges still lie ahead: adult services with its many mountains to climb.



What further outcomes are needed to ensure people with PMLD have the support necessary to help them navigate successful life transitions?



These life transitions require considered approaches that support families and the person themselves to safely navigate and be emotionally supported through the complex maze that is the current system.

We need to remember the stories of the siblings to and the question of a 6 year old already worried about “who will look after my brother when you and super Dad go to heaven?”. Their wisdom and compassion needs to be harnessed in considering the solutions for support for everyone to live their best lives.

What would my sister like too?



“I can have my childhood, if you promise my brother will be looked after, when mum and superdad go to heaven.”

Lifelong Learning



Once children leave school and enter adult services there is little in the way of continuing education and lifelong learning for people with PMLD. Children and young people with PMLD are recognised as having a right to access education but what happens when they reach 18?

Our experience is that there is little, if any expectation that adults with PMLD will access further education and what little there is tends to be focussed on life skills.

Family carers are now advocating for their adult family members to have access to life long learning and asking that this is planned for while they are in secondary education.



Lifelong Learning



People with PMLD and their families would like to see a lifelong learning model that works within existing colleges of further education. A model that offers students of all courses an opportunity to get to know and understand people with PMLD by being students together,

For example sports students and occupational therapy students could be introduced to adapted games in their course and students with PMLD could attend the sessions to show them how to undertake the activity and teach them how to be inclusive. They also teach how to communicate, how to be compassionate, how to adapt and be inclusive and how to work as a team.. This is a meaningful and cost effective way to bring the two together to further the learning of students and to provide a sense of belonging to people with PMLD.

The same could be applied to art and drama students. Mainstream students get to choose their courses so why do people with PMLD not have the same opportunities for lifelong learning through teaching others and mixing with young people.



Education and Lifelong Learning



People with PMLD are such an easy group to ignore because they're so often seen as someone else's responsibility. We need to try to learn how to walk in their shoes so we can remove the cloak of invisibility that surrounds them.

PAMIS COLLEGE

Just Imagine what I Can do
By Lauren Graham



Bereavement and Loss



End of life is never easy for anyone but for people with PMLD the loss of a parent also means the loss of the person who is also an expert by experience in the way the person communicates, their care needs, and in many cases, they lose their legal guardian as well.



All of this on top of having to make sense of the concept of death. These are very complicated ideas to get our heads around, so for a person with learning disabilities, understanding these can be much more difficult. How a person experiences bereavement, however, will be only partly to do with their level of development.



Regardless of age, ability or sensory capacity, people with profound and multiple learning disabilities do notice changes in the environment surrounding them and in their relationships.



Bereavement and Loss



People with PMLD may experience loss in similar ways to those without PMLD or indeed without learning disabilities. They may be experiencing the following, but many are difficult to determine, for example: Confusion (e.g. about where the deceased person has gone); Anger (e.g. towards the person who is no longer here). Fear (e.g. of going to sleep). Loss of care from the person; Feelings of abandonment, insecurity and separation anxiety; Greater dependence on others and limited realisation of death; Changes in their routine and activities; Lack of confidence in relationships; The need to search for the person; Guilt (e.g. feeling that they caused the death); Frustration (e.g. at people for not understanding their loss and not being able to express themselves) ; Secondary losses (e.g. a person may not see their Grandfather anymore because it was Dad who always took them to see him, but Dad died). Such complexities are often not understood by those left to support the bereaved person. Similar emotions are experienced when support staff or those familiar to someone with PMLD leave but no planned ending has been put in place.

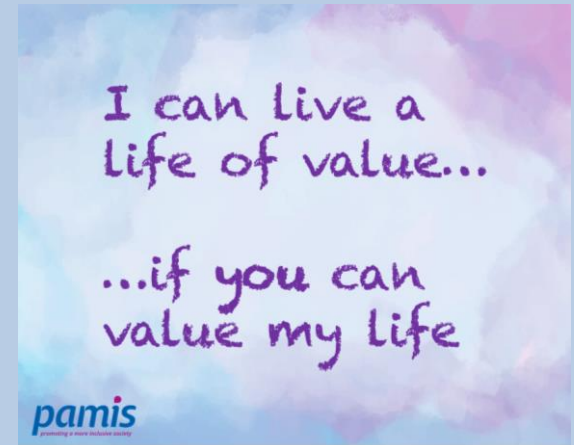


Policy into practice: When your story meets my story, we can learn together



If when we are making policy we ensure we “walk” with those who are impacted by it we may then create policies that consider the most marginalised and moves us towards a Scotland that includes and involves everyone.

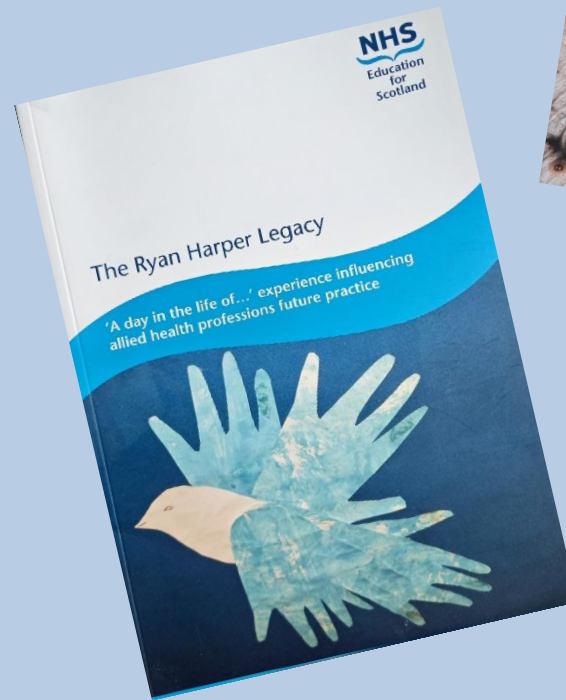
The families we support are currently asking if we can develop standards for people with PMLD as they recognise that this group of people are still excluded, ignored and invisible. The risk is that this will further exclude but what if any future policy development “walks” a person with PMLD and their families through the draft to see how it might impact on them before implementation.



Policy into practice: When your story meets my story, we can learn together



PAMIS worked with NHS education for Scotland several years ago after family carers highlighted development needs of healthcare professions. They suggested that communication, empathy and an understanding of their lived experience would be useful to support person centred care. The Ryan Harper day in the life experience is an excellent model to support health and social care practitioners at all levels to understand the complexity of care and consider how to deliver person centred interventions.



The Ryan Harper Legacy



A mum told her experience of how an appointment early in the morning impacted on her, how many barriers she experienced in trying to get to the appointment and the negative experience she had when, through no fault of her own, she was late in arriving. This story when told to a group of AHPs impacted, each profession could see how this could have happened in their service, how experiences were not considered, that there were opportunities to make things better. The Ryan Harper Legacy, a day in the life of experience, supported AHPs to spend time, at specific points of the day, with a person with PMLD and their family. Being a part of the family life highlighted what was important and enabled practitioners to understand how their routines, processes and assessments impacted on the caring role. Insights gained by the practitioners undertaking the learning opportunity changed practice. The families also developed an understanding of the challenges faced by the practitioners.

The reflections expected during and after the experience support a model of learning that should change practice, should support co-production, could influence future policy.



I Can if You Can make policies and research a reality



I can if you can ...
make policies and research a reality e.g.

- Play Strategy for Scotland
- “Give children the resources and they will include everyone” (Diamond and Hong, 2010)
- United Nations Convention on the Rights of the Child (UNCRC)
- GIRFEC (Getting it right for every child)
- The Promise
- Equality Act 2010



What further outcomes are needed to ensure policy and practice support children and young people with PMLD to live the best possible life they can?



If the voices of the families' are listened to, heard, and appropriately acted on at a local level policies would be put into practice in a more appropriate way.

Too often as policy filters down from government it is interpreted locally in different ways and it is then not implemented in the way it was intended.

For policy to be put into practice effectively it has to have the necessary framework and understanding available at a local level. Stories and narrative support an understanding and context.



I Can achieve great things if You Can:

- Listen to my voice with all your senses.
- Understand that my life is valuable, not just vulnerable
- Imagine how much better my life could be
- Recognise that I have dreams and ambitions
- Respect my human rights
- Help me to access what I need
- Appreciate how much value I can add to your life

I can if you can – presentation

I can...

play video games,



shop till I drop,



sit ski.



I can...

do karate,



do fun.



sing along to all
my favourite music,



I can...



swim



and splash!

I can...



paint,



collage,



paste,



colour,



create,



draw.

Part 2- Why Stories



The Value of Stories



Stories are everywhere in our everyday lives, they surround us. Stories help us understand the self and others. They support learning and development, understanding, interaction, engagement, connection. Storytelling and narrative are woven into the fabric of our history and culture.

Personal stories are powerful narratives that offer valuable opportunities to contribute to systems change, culture change as well the values of society.

Engagement through stories and storytelling takes many forms and the creative process of researching, crafting, designing, telling and retelling of stories offers many opportunities to capture and harness these stories to help gain a better understanding of how together, we can create a community of awareness, understanding and compassion. Engagement through stories and narrative captures and reveals the barriers and enablers that people experience in their lives and through this engagement process we learn so much about people's lives and the way they engage with the world.

Learning through story offers the opportunity for change in many ways. It offers new perspectives, new possibilities to reshape existing systems and it builds empathy. The value of stories in reshaping current ways of working offers new possibilities through the authenticity of the voices of the story holders.



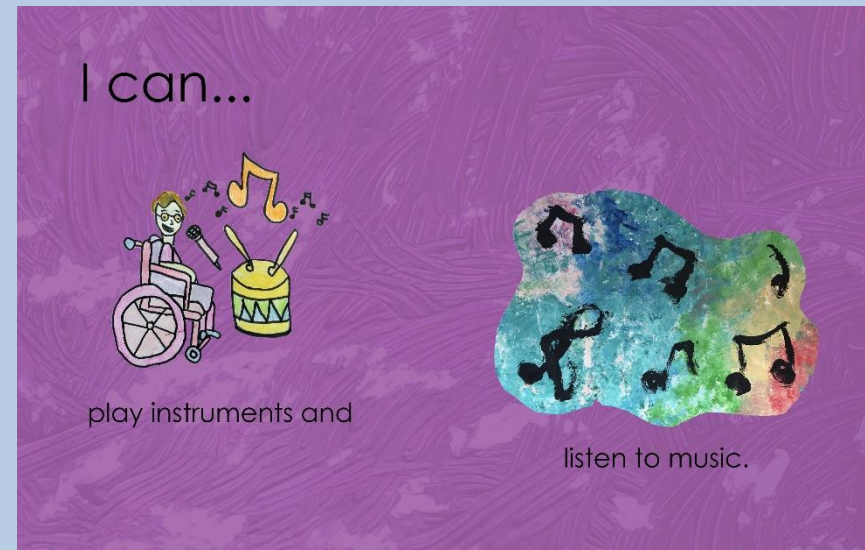
Why Stories and what might a practical storytelling toolkit contain.



This is an outline of what a story toolkit may contain. It is by no means the full toolkit.

Each of the sections discussed have been included because of their robust research and theoretical framework, but this resource does not have the time or capacity to expand on this. It will be acknowledged where appropriate.

The focus of this resource is to show how engagement through stories can enhance the understanding of the lives of people with PMLD. This section of the resource provides examples of how this can be undertaken.



We are our stories



A good toolkit should always emphasise that we are all story holders, makers and tellers and we are the stories we tell ourselves. We are shaped by our own stories and influenced by the stories of our ancestors, by those who enter and influence our lives and ultimately we are our stories. We have a right for those stories to be heard if we wish them to.

Our lives and their pathways are not fixed in stone; instead they are shaped by story. The ways in which we understand and share the stories of our lives therefore make all the difference. If we tell stories that emphasise only desolation, then we become weaker. Alternatively, we can tell our stories in ways that make us stronger, in ways that soothe the losses, in ways that ease sorrow’.

—David Denborough



The Charter of Storytelling Rights – David Denborough



This charter of storytelling rights is the framework and basis for all of the story work undertaken by PAMIS.

The Charter of Storytelling Rights

Article 1. Everyone has the right to define their experiences and problems in their own words and terms.

Article 2. Everyone has the right to have their life understood in the context of what they have been through and in the context of their relationships with others.

Article 3. Everyone has the right to invite others who are important to them to be involved in the process of reclaiming their life from the effects of hardship.

Article 4. Everyone has the right not to have problems caused by trauma and injustice located inside them, internally, as if there were some deficit in them. The person is not the problem; the problem is the problem.

Article 5. Everyone has the right to have their responses to hard times acknowledged. No one is a passive recipient of hardship. People always respond. People always protest injustice.

Article 6. Everyone has the right to have their skills and knowledge of survival respected, honored, and acknowledged.

Article 7. Everyone has the right to know and experience that what they have learned through hard times can make a contribution to the lives of others in similar situations.

Multi-sensory stories, their uses, and benefits



The development and journey of PAMIS multi-sensory stories began over 20 years ago and was based on the model created by Chris Fuller of Bag Books. Pamis further developed the model following research undertaken through the SEN Innovation Grants Programme.



The research focused specifically on developing literacy skills through multi-sensory story-telling in children and young adults with PMLD in 2012. Aimed at improving literacy skills the programme successfully created 50 personalised sensory stories over a two-year period with parents, carers and staff from schools and centres in 5 areas across Scotland.

A journey with multi-sensory stories



This was a very successful project and to date these stories are the most borrowed item in the PAMIS library and the research was further replicated and developed by European researchers.

The programme was titled Real Lives Real Stories and the stories developed for individuals were all based on real life events experienced by the young people. The development of these stories involves the story practitioner collecting appropriate information from the family, Occupational Therapists, Physiotherapists, Visual Impairment specialists, (functional vision assessment). Gathering this information for every individual is crucial to support the design and development of a personal story.

Sensitive Stories



Sensitive stories followed the multi-sensory story model of individual story development but concentrated on helping people with PMLD to understand difficult life experiences. For example how do Children and young people with PMLD understand their body changes as they grow up? How do they prepare for a visit to the hospital, the dentist etc? Sensitive stories are a great way to prepare people for situations that might distress them or upset them. Going to the hospital or the dentist for a planned admission for example might be stressful for some so preparing a multi-sensory story tailored to that individual might greatly help them.



You can also use this method to prepare someone for a visit to the theatre or a visit to the museum. Everyone will have their own way to access story but the key is to be forensic in your information gathering before you create a sensitive story, that way you will eliminate possible triggers and the person with PMLD will hopefully enjoy the visit.

Oral Stories and The Mythical



In this section we move on from personal stories to the oral tradition and the mythical. PAMIS also weave Tangible and Intangible Heritage together by working in partnership with museums, art galleries and trusts to connect stories to art and exhibits. Nature events too offer the opportunity to connect with stories of the land and the natural world. Both Tangible and Intangible Heritage have huge potential for creating learning resources for people with PMLD. They also offer people the opportunity to explore the stories through a therapeutic lens. The personal and the mythical are not separate and the oral stories, folktales, legends etc, offers another lens through which to view and explore personal life experiences. Viewing life experiences through traditional legends and folktales also offers the opportunity to help explore complex relationships and emotions.



Welcome to
HMS Unicorn

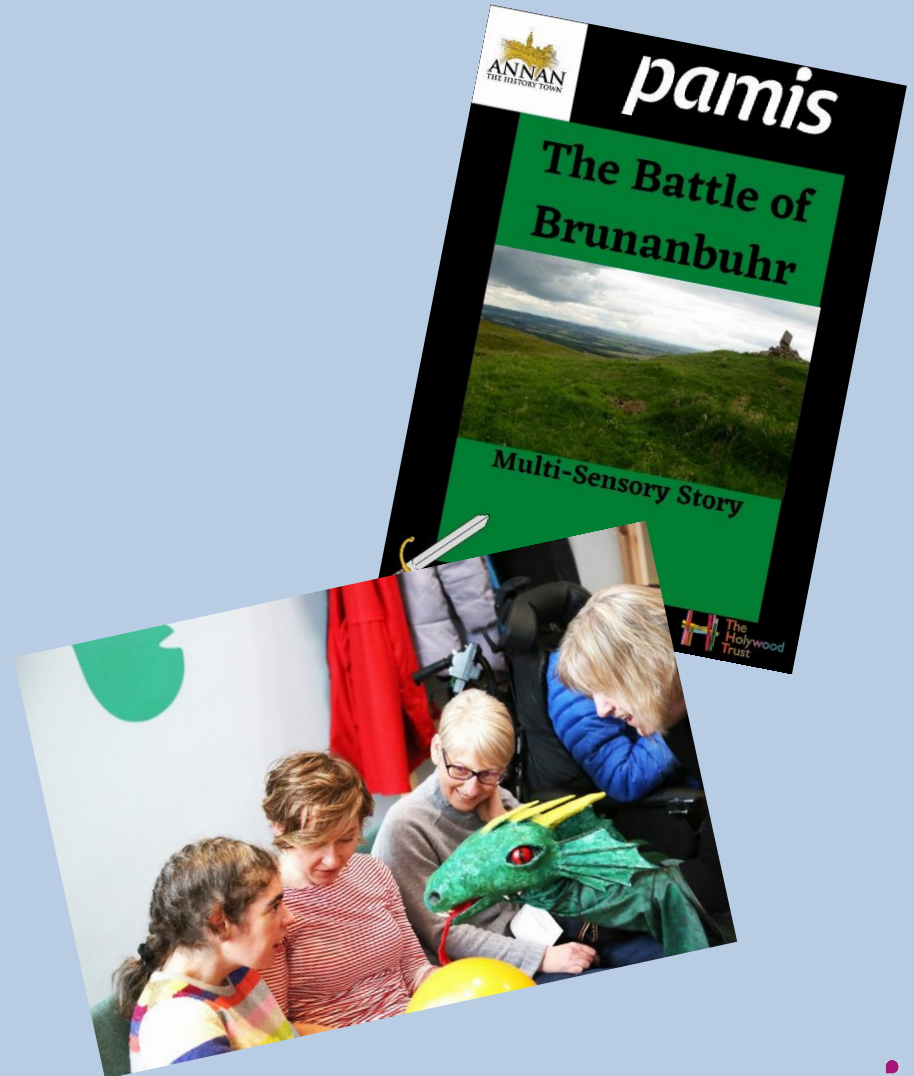


pamis
promoting a more inclusive society

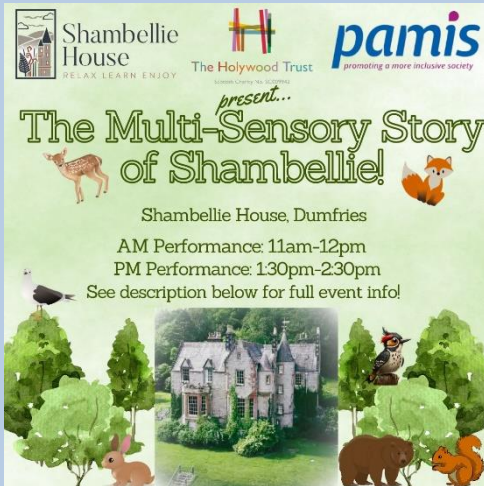
Stories for social connection



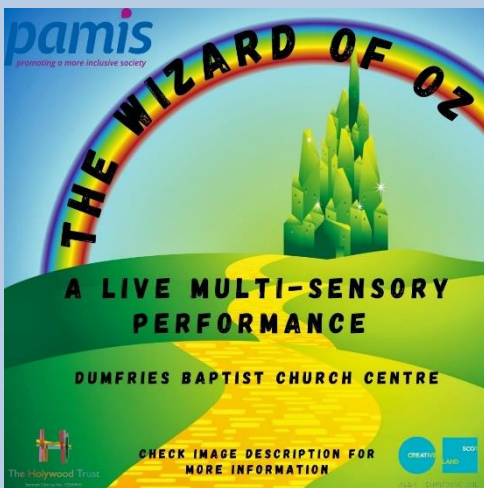
Oral stories also facilitate engagement, interaction, and connection. They provide opportunities for socialising and gathering together to enjoy friendships and new opportunities. They provide a different experience and can be told at festivals, in halls, in schools and can offer an immersive experience for those attending the story sessions. Attending these stories offers people with PMLD the opportunity to engage with a different type of experience in a different way and in different environments.



Performance stories for Social Connection



These offer opportunities to connect with the story in a very different way from the personal stories yet offer the opportunity to explore how the personal experience relates to the story. These are more performance stories that offer an opportunity for a more theatrical experience either as an audience member or a participant. .



Digital Passports, life stories, family histories and anecdotes



Exploring someone's life story can help staff supporting people with PMLD to have a sense of who the person is and what they enjoy in life. Having an understanding of a person's life story and the barriers they have overcome in their life helps support staff to understand someone's behaviours too.



This is especially useful if people are getting to know someone with PMLD that they have no background information on. (more on this was described in the digital theme earlier in the resource)



I am Jack - I AM A SAILOR



We remember Jack, with a smile that lit up the world and a personality to go with it! He sadly died In the summer of 2023, but his family wanted him to remain a part of this resource. Indeed his mum said he always loved to be in everything so it would be his wish.

I am a sailor and an artist. I am famous.



Here's a short video
Of me sailing my boat.



This Is Me !

By Jack McBride -

"Captian Jack"

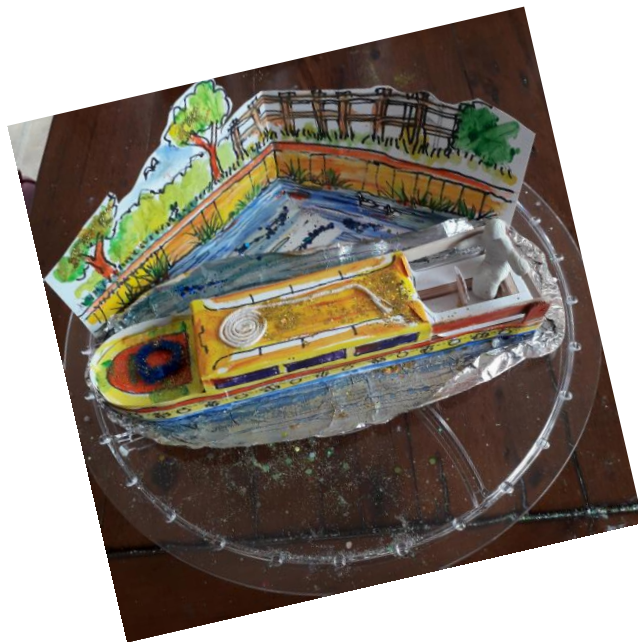
This is my story of why I made a canal boat on the canal to describe myself. I'm an artist and I like to make lots of different things to show who I am especially as part of Pamis online Art group every Monday with David Grigor of Blind Create.

It was obvious what I wanted to do for my project, I'm called Captian Jack because I steer a special canal boat on the Lancashire canal every July for over 10 years and I love it. Let me tell you about how I made my proejct.





I wanted to make a canal boat on the canal with me steering the boat, so to start with David showed me example of what I could make. With support from mum and support, I then I needed to make a boat.



To start with I used lolly sticks to begin the canal boat. We used PVA glue and put several lolly sticks together in a row and 2 in front. We then cut some sticks to make the sides like laying bricks to build the boat. Just like this:



Then:

When the canal boat was dry after glueing I started making some of the features for the boat and used different things to make them such as colour clay shown here:

I chose particular colours and different textures for the boat.





Then it was time to do the back ground and make the canal. I used silver foil, bubble wrap and shredded paper to look like water and the canal boat moving through the water (just like the words in this sentence!





Then I finished my display by putting corrugated card at the back and paper with a picture of the canal bank and a landscape.

I used a lot of different materials to make this whole project and chose colours, materials and chose where to put them. I really enjoyed putting them all together and hope you like this as much as I do.

I'm holding the box for the cake stand that my artwork is proudly sitting on:



Storysharing



Storysharing was developed by Dr Nicola Grove who describes it as enabling children and adults with communication difficulties to remember and tell their stories of everyday life.

The focus is on what they CAN do to contribute. It's based on the way we all share experiences in conversation, and on research studies.

Research shows that personal stories are how we make sense of what happens in our lives – they are central to our sense of who we are

- 65-80% of communications relate to a personal experience.
- We make and keep friends through sharing stories.
- Telling our stories can lead to social change - it's empowering.
- The ability to tell a story helps with communication, language, and educational achievement.
- Sharing stories helps to build recovery and resilience after difficult times.
- Telling stories is creative and fun.

Storysharing



Leo loves to tell his swimming story

My Swimming Story

"the water was lovely and warm..."

"I saw my friends ... we splashed and splashed..it was really fun"

*Sharing stories together and being involved in telling your own story is a very powerful and liberating experience **and again each person will convey their story in** their own way with support. Co-telling a story with someone with PMLD provides the person with a sense of control over the story. (Grove, 2023)*

<https://storysharing.org.uk>



The Importance of the therapeutic storytelling space (External and internal)

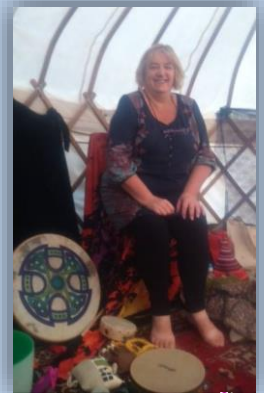


The Story Space

The story space is a magical space. It is the place of exploration, imagination, and transportation. The story space will take you on a journey into the story fields that are a part of you and a part of those around you. The story space will take you wherever you want to go. The story space is a place of understanding, knowing, trusting, listening and being present. To be present with someone in this space is an honour and a privilege. The story space is where the magic begins.

It is important to think about this psychological space in this way. The psychological space created by the story allows for externalisation of emotion – the child / person doesn't internalise the emotion but sees it as separate from them and the strength / unique qualities that they bring.

To enable the exploration that the story space it is beneficial to also respect the physical space in which the story is told – Is it cosy/welcoming/accessible etc?



The Importance of the therapeutic storytelling space (External and internal)



Whether the story space is online or in person, it is worth taking time to think about the space.

In our busy lives we all love those spaces in life that calm our minds and offer time for contemplation.

Having time and space are the two precious commodities that fuel the creative process. For people with profound disabilities, it is no different.

Out in nature under a tree can offer a multitude of opportunities to create a story space.

The Importance of the therapeutic storytelling space (External and internal)



If indoors, find a suitable quiet room or therapeutic space that can be set out nicely in a calming way.

Using a particular smell that people associate with the space is useful, as this helps people begin to recognise the space as one where stories take place.

Being outdoors making and telling stories is great fun too and story walks can be riotous affairs or gentle strolls, depending on the topic, but again it's that knowing and being present with the person that is important in any story adventure.

The space can be used for individual story exploration or for sharing stories with others. If sharing stories with a group, it may be an idea to set up the story space to accommodate the individuals in the group.



The Importance of the therapeutic storytelling space (External and internal)



Sometimes when working with a small group in the story space there might be someone who finds the story overwhelming. In these instances you can create space within a space where the person might want to go to feel safe or more relaxed. One fun way to do this is to create a den in the corner of the story space or in a space known to the person.

Below we have taken some chairs, covered them with a sheet and laid out a quilt, some cushions and a soft toy.

I'm sure you'll have lots of ideas of your own! But it is important to remember to keep people feeling safe and valued in that space.



The Importance of the therapeutic storytelling space (External and internal)



The internal space.

Our lives are a series of events, some of which are formed into storylines that shape our identity. The story space is a safe space that can support the exploration of these events and the associated emotions that may surface during the story making or telling of these events. Often, it's difficult to make time and space for the exploration of the emotions we may experience during life events. There is no more precious a gift than to give someone the time and presence to listen to their story.



The Importance of the therapeutic storytelling space (External and internal)

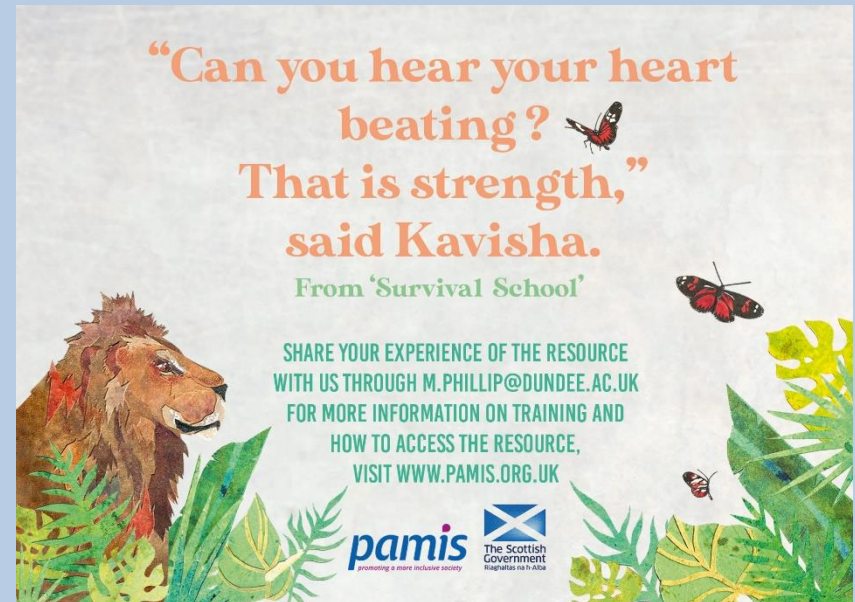


Emotions such as sadness, happiness, anxiety, or anger, however it is conveyed, can all be experienced through a story, whether that's a story of a real-life event, or a fictional story.

The story space allows emotions to be seen and validated in a safe environment, that allows an exploration of the emotions.

Our storylines are also inevitably influenced by the political, cultural and social influences around us and this makes it difficult to separate ourselves from past experiences.

Be aware when you create and step into this space the stories you hear might have a powerful impact on both the teller and the listener.



The Importance of the therapeutic storytelling space (External and internal)



Working with story can also enable old stories to be reshaped and retold in new ways. The story space in this resource is central to supporting the exploration of emotion through real life stories, fictional stories and drama, music or dance. The story space is your space to explore whatever you want to explore.

**Note Be aware that your story can directly impact on another person's story, so it is important to consider the impact your story will have on the other person's story when you step into that space.*



The Importance of the therapeutic storytelling space (External and internal)



Presence

Stepping into the story space with someone to spend time creating or telling multi-sensory stories is a very special experience. Stories connect people, and being together in the space is a unique opportunity to be present with both the space and the people in the space.

In this instance being present with someone means that you are with them authentically, in the moment.

Through being present in the story space with someone with profound and multiple learning disabilities you are there with the person, and you hold awareness, understanding, engagement and compassion. By being present with the person you will observe more about the way they communicate, how they react to their story and how you react to them.

The story space is a place of learning, understanding, communicating connecting and having fun.

Enjoy the story space.



The Importance of the therapeutic storytelling space (External and internal)



Trust

Trust is important in the story space. Being present with someone in that space and responding appropriately with the person you are creating or telling the story too helps to build trust. The way you respond during your time together will help to build trust. To offer information about personal emotions, whether that is through language, reactions or behaviours is hard to do if you do not have trust.

Being present and building a trusting relationship is an important part of the story space. Below are some examples of things you can do in the space to help build trust.

- Breathing exercises, Butterfly hugs
- Favourite Smells, Sensory toys
- Drumming together, Catching bubbles

Creating an 'environment of nurture, consistency, predictability and kindness.' De Thierry, B (2017)

Be together in the story space.

I can be a sportsperson



pamis
promoting a more inclusive society

Summary and Next Steps



Summary



Thank you to the storyholders who willingly shared their stories in this resource to support and advance approaches to meaningful engagement with children, young people and their families. It is only by sharing stories that meaningful engagement will lead to appropriate action .

Thank you for taking time to read the stories in this resource as it is only by getting a glimpse into the lives of people with profound and multiple learning disabilities that meaningful engagement can take place.



If we get it right for people with PMLD we get it right for everyone

Let's listen to their stories

Training in all of the storytelling methods mentioned in this resource are provided by PAMIS.

Next Steps



We want to have the same opportunities in life as everyone else

