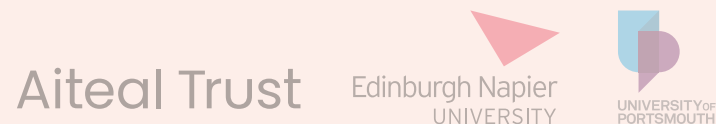


Louis's

**The Story  
of Appletree**

Story

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# Louis's Story: The Story of Appletree

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PART ONE

## The Purpose of this Project

- To raise the visibility of people with profound and multiple learning disabilities and autism who as a marginalised group of people are imprisoned, abused and ignored along with their families.
- To conceptualise loving justice and forgiveness in addressing systemic disablism.
- To develop theological reflection and action as a new way of creating communities for profoundly vulnerable people within the context of social policy and its implementation.
- To develop resources for empowering the informal sector and the building of intentional communities to address those systemic problems



Who is

Louis?

knowing who Louis is  
involves knowing ourselves

We can never know who Louis is ... at the same time we must also ask, who are we, who asks?

We start from a point of unknowing, of humility and curiosity .. of relationship and love, or at least goodwill, towards Louis, and to ourselves and others in our global human family.

We understand Louis is the same as us. At the same time we find Louis is different. For a start, his communication impairment and his cognitive impairment strip him of power to speak for himself as we do. It follows, ethically, that we who have capacity have moral obligation to connect, should seek to enable Louis to be himself and to relate to us and his world.

Louis shows up the  
limits of the study  
of knowledge

Since Descartes, the power to speak for oneself to claim irrefutable truth, 'I think therefore I am', has underpinned epistemology, the study of knowledge. Familiarity with Louis, who is, in and of himself, a 'limiting case', shows where this paradigm about human knowledge breaks down. Familiarity with Louis leaves us with relationship, with Being, with awe. Louis has a word for this, which I spell 'Eeeee'. It is said by Louis, in a gentle tone, towards and including Other.

E



Louis 4th October 1986 — two days old

Neurobiological  
framework  
around who  
Louis is

The neuro-biological description is different from Louis's life-force, his intelligence, his emotional coherence, his lived experience over 36 years, his joy, capacity for love, relationship and self-expression.

Louis as a newborn baby developed *Proteus mirabilis* bacterial meningitis. It is a rare condition, 11 babies in UK in 1986 had it, he was one of 2 babies to survive. His white cell count the 2nd highest ever recorded world-wide. He survived effects of intensive care too.

## Effects of neonatal neurobiological history

The physical consequences of his illness were severe. *Proteus mirabilis* is an invasive bacterium, which destroys brain tissue, forms abscesses. After surgery to drain them, Louis was left cortically blind, with scar tissue causing epilepsy that continues up to now. He lost capacity to speak, along with verbal, numeric and abstract reasoning, capacity to see another's point of view.

Recent evaluation of Louis's understanding, using standard psychological testing places him at 18 months developmental age. This is the age where a child is needing to be 'made whole' by Another, while developing independence and agency. The child does not understand anybody else's but his own point of view. Louis's autistic features, therefore, may be effects of meningitis.



## The importance of relationships to know who Louis is

We need to see the importance of relationship to somebody at Louis's developmental age, to think who Louis is. Like an 18-month old, Louis is dependent on a full-time caregiver. Through Louis's early life, his mother, Kate, was constantly with him. She enabled him to be himself, was always planning ahead on his behalf, communicating with him, negotiating between him and the world, keeping him emotionally safe, sorting out problems, giving him confidence in himself and the world. Louis needed this quality care then and still needs it.

We think of a person as an individual physical body, to be DNA-checked, to whom we attribute human rights. By contrast, Louis shows a person is intrinsically relational, dependent on love, nurture, recognition, that both in turn nurtures the other.

Renaissance paintings show inherent relationship between Mother and child, the power of Love, Constancy, Grace that is the unsought gift, given in return.





## How the loving other frames reality

To know Louis, we have to look at Kate, her Christian faith. She says it includes awareness of:

- the constant love of God
- equality of all people before God
- God's desire for justice and right relationship with all people
- God's preferential option for the poor
- God's invitation to us to trust God's love
- God's invitation to us to co-create the kingdom of heaven
- the power of hope and faith and love
- our need to align our Will to God's will - let go and let God
- centrality of forgiveness
- the gifts of grace

Spirituality as a core life force irrespective of intellect or creed.  
Models of community, including the Bield, Benedictine, Iona.



## History of Louis's care

Louis's lifelong care-needs have not changed from his early years. Ordinarily children develop independence, allowing parents to reduce attention, but Louis's remained the same. Kate's capacity to meet them grew less with two younger children to care for alongside. She was promised by the paediatrician 'Society will always care', so she held the state accountable, asked for help.

Social services funded day care, then live-in care while Louis attended special needs nursery. Aged five, Louis took up weekly-boarding at the Royal Blind School Complex Needs Unit, in Edinburgh. He got the full-time attention he needed, and sensory integration to help his visual-impairment. From then until he left school, Louis weekly or fortnightly-boarded. This still left holidays which were very demanding for Kate. Friends helped by caring for Louis's two younger sisters, who later went to boarding school.




## Lack of adult social care provision after school

After school, there was no suitable housing, care or community living available. Louis left school in 2004, spent seven weeks at home, where Kate could not care for him single-handed. He then had his first experience of unsuitable care in community which broke down, leading to his first admission to hospital. It was clear that Louis needed skilled staff who needed support, routines, purposeful activity, security, suitable housing.

In 2006, with no alternatives, Kate chose for Louis a quality care provider who had opened a home in Hampshire. She flew between Scotland and the New Forest fortnightly to visit. Louis had regular family time in a cottage nearby. The home never flourished and shut in 2012. Louis left in 2011, after a vacancy arose in Glasgow in a long-established home with 9 residents. Louis lived there for six years, visiting home fortnightly until he was evicted when it shut in 2018. There was no other care. Louis was sent out of country to Hartlepool, brought back to Perth for 7 weeks, then admitted to hospital start 2019. He remained in hospital, on a locked ward - first Carseview, then Strathmartine - until May 2022.



Louis and Kate - 2011 - out for Chinese supper



Independent pursuit  
of medical  
negligence action

Kate pursued a medical negligence action from 1989, on the grounds that with appropriate treatment Louis need not have developed meningitis. In 2006, the case was settled out-of-court. It was not full lifelong costs, to take Louis out of reliance on local authority funding but was a significant sum. It paid for Kate to travel to the New Forest to support Louis in the only care setting available and bought a cottage to be home for Louis there. After selling that, it bought the buildings for Louis's long-term home, Appletree, contributes to Louis's living costs.





Louis painting - 2023 - Appletree painting

This is a story about you, *Louis*, it's about you and mum, going for a walk on the beach at Westward Ho! a long time ago, when you were at Oaklands Park School and we lived in Bideford.

Once upon a time ... *Louis* ... we drove in mum's car to the pebble ridge. We parked and we climbed over the pebbles. And at the top, when we looked for the sea ...

*It wasn't there!*

And you laughed, Louis! We looked at each other and we thought

*That's funny!  
where's the water gone?  
it isn't there!*

Mum said, 'let's take off our shoes ... one shoe, two shoes ...'

'Take them off!' you said.

Then you ran very fast towards the river ...

Mum was a bit frightened, she ran after you, because the water was going out to sea very quickly and Mum was afraid in case you went in the water and the water took you away.

You felt annoyed Louis, because Mum was stopping you going in the water. But you didn't go in, you stayed on the sand with Mum. She told you she loved you, you smiled back at her.

'mummy loves Louis  
you said back to her.

You were happy, Louis, we were walking on the sand,  
in the sunshine. You started running.

You wanted to run across the sand as far as you could see  
towards the sea. It was a long way off, you liked running. Mum  
was running too and that made you feel safe. We ran and we  
ran. The sand was hard under our feet.

We ran until we got to the place where the  
river met the sea and there was no more  
sand. Then you slowed up and stopped.  
You turned round and smiled at Mum.

Our running had made you happy.

You were feeling full of love and you sang a song with  
the word 'love' in it, that goes

The king of love  
my shepherd is.



Mum said, 'Oh Louis, I didn't know you know that song. I do love you, Louis.'

You heard the love in Mum's voice, you pulled her head towards you so you could kiss her, then you giggled and started singing the tune again.

I don't know if you remember that day Louis?  
Mum remembers it, Mum will tell you the story.

I know you remember the tune.




This project tells the story of Louis Sainsbury and the development of the Appletree Community. Appletree is an intentional community for one, providing a home for Louis which enables him to flourish and fulfil his potential. Louis is a survivor of meningitis, who has profound and multiple learning disabilities (PMLD) and autism and was one of the 67 people trapped in secure settings in Scotland and contrary to their human rights.

The Scottish Government's Coming Home Implementation Report has held Appletree up as an exemplar of what can be achieved, and Louis's experiences prior to release as an example of all that is worst in the systemic abuse and neglect of people. Louis has brought together a team of researchers from the Universities of Portsmouth and Edinburgh Napier to co-produce with himself and key stakeholders in the development of Appletree an account of his story. That story is ongoing and through engaging with it you are now a part of it and we invite you to journey with us. What Louis and his family and the research team want to achieve is not simply an account of his journey but also an in depth understanding of how people with PMLD and their families are overlooked, under-supported, and at worst, neglected, abused and forgotten.

This narrative outlines the vision, the implementation and the sustaining of Appletree as a long-term home for Louis. Much more than that, it uncovers Louis's voice, reveals his role as a leader, change-maker, and inspiration. Louis and family have brought together a 'research' team of practitioners and academics to share and co-produce their story for the benefit of others and with the hope of real and permanent change.

[Link to report](#)





The view from a mother invited to contribute her son's story as a case study in the government Coming Home report: What it is like living in Scotland with a complex and profound learning disability. Kate comments on this five years later, that in having to negotiate the complexities of the political, financial and economic landscapes she was overlaying her knowledge of Louis as a person with the official language of "care needs." Kate observes that families as primary caregivers have to become adept in using this language to try to obtain resources for their loved ones. Furthermore, this risks reducing their loved ones to an economic commodity which denies humanity and reinforces the negative stereotypes about the true value of people with learning disabilities. There is a fundamental misalignment between rationalised, bureaucratised and economic state systems as gatekeepers of resources and the actualisation of love necessary to be a flourishing human being.

## From the coming Home Report:

"

Louis is in his early 30's and lives with Complex and Profound Learning Disabilities (PMLD), and is also autistic. He had enjoyed six years of high quality of life in a care home, with a stable staff team who understood his 'language' and needs, until the home's closure was announced. Ordinary Place of Residence rules meant there could be no continuation of care staff with a change of designation to 'supported living' as the local authority stood to gain responsibility for all 8 additional placements. Residents were therefore to be placed by their own authorities.

Louis's mother and social worker searched for an alternative placement however there was nowhere in Scotland. Louis's mother began planning for long-term solutions, but soon found nothing was achievable within the six months' notice period. As Louis faced eviction, a home was identified in England, 250 miles away. It was privately run specialising in 'challenging behaviour'. The facility was far away, institutional, but there was no alternative and so Louis was moved there. Louis's mother had no option but to travel to visit him there.

"

No transition was offered for Louis or his new care team. Instead, Louis's mother drove him there personally, staying overnight at personal cost for days and weeks to offer reassurance and love to Louis. Given her expert knowledge of caring for Louis she was able to assist with training staff and she returned weekly to support this transition for Louis. The primary barrier for Louis and staff was communication. Staff did not understand what Louis was saying and vice versa. This emphasised a power imbalance. Louis needed skilled care that accounted for his fear, bereavement and homesickness. However, staff were relatively inexperienced and unfamiliar with Louis, with no professional support for therapeutic approaches. They were required to do a job that was more skilled than they were equipped for. Louis expressed himself through the only language left to him: destructiveness towards property, and aggression to people.

'The facility was far away, institutional, but there was no alternative'







Appletree Neighbourhood Garry, Louis, Kyle, Jane - 2023 - Appletree

Louis's challenging behaviour was managed through restraint, which was both pharmacological and physical in nature. Over three months, the cycle of restraint and protest grew. It was traumatic and injurious for Louis, his mother and staff. Professional services within the facility were later engaged including clinical psychology, speech and language therapy and occupational therapy. Louis's desire to return home was identified as a major factor in his distress in reports, along with his need for skilled communication, routines, a mix of activities, and a greater understanding of autism and complex needs. Local authority commissioners noted the consequent rise in costs. Nobody from the commissioning team ever visited.

' A greater understanding of  
autism and complex needs '

As costs rose towards £6,000 per week, the local authority planned to bring Louis back to Scotland. They identified a vacant city centre flat, managed by one of their social care organisations. They proposed care provided by two organisations, one of which had previously been commissioned and another organisation, who had been originally designated for Louis's long-term care. Louis's mother objected, as did managers from the second care organisation. The flat had no garden, no safe access to outdoor spaces. Combining two care organisations created complications in delivery of services. The family and senior managers' objections were overruled.

Louis returned to Scotland to the new care provision, again without transition. Recruitment and retention of staff was a problem, even before Louis arrived. The primary barrier between staff and Louis was communication. There was a lack of skilled care suitable for Louis's complex and profound needs.

After seven weeks, Louis was admitted to the NHS Learning Disability Assessment Unit under non-clinical crisis following service breakdown and challenging behaviour. Louis remains in the unit 3 years later.

' There was a lack of skilled care suitable for Louis's complex and profound needs '







Kiltwalk - 2016 - Louis and Thomas Smith - Ballach





Louis has been detained in hospital for three years. He was declared ready for discharge in April 2021 and has been in transition to his own home since February 2021. His experience of hospital can be characterised as 'containment', with lack of meaningful occupation, poor therapeutic understanding of his verbal communication, who he is as a person (his spiritual needs), resulting in unhappiness and protest behaviours.

Louis continues in transition to his own home. It has taken sixteen months to date. The major constraints are recruitment of care staff and development of systemic management practice to ensure all staff are skilled and confident in supporting Louis. Louis's underlying needs are profound and multiple, requiring flexibility and ongoing learning for individual carers, managers, the care organisation, commissioners, Louis, and his mother, to integrate and use available resources. As Louis's mother I have led the project, motivated by Louis's best interests. I purchased accommodation, as Deputy to the Court of Protection; I also exercise an oversight and integrating role, as Welfare Guardian.

## DR ANNE MACDONALD

### Why hasn't there been more change since the Coming Home report?

- This is a complex issue which needs to be addressed systemically, through a whole-sector approach. There are lots of examples of individual discharges for people with complex needs being done well, and people with previous histories of failed support are now living well in their communities. But as a sector we are still working towards adopting a whole-system approach to this issue, in a way which looks at how the different factors influence each other. This means making the connections between delayed discharge and the lack of community resources; between the different rates of pay in health and social care; between a commitment to increased short-term spending, to achieve longer-term savings. There are many different parts of the health & care system which need to work differently, and together, for the change outlined in Coming Home to be a reality.
- There remains a significant range of issues in social care that continue to make successful hospital discharge a challenge.
  - Recruiting & retaining staff; fair and equal pay across the sector is an essential element of this.
  - Ensuring staff have the right skills for supporting people with complex needs; additional training and practice-based guidance is required to develop staff with the right skills for working with people with more complex support needs.
  - Staff need to be well supported in their day-to-day job; practice leadership is essential, not managers that are distant or office-based; this type of staff support needs to be sustainably funded
  - Social care services tell me they are not commissioned with sufficient budget to provide all the non-direct contact time that is needed for supporting people with complex needs, e.g. staff training, debriefing, coaching & mentoring, staff wellbeing, team meetings staff supervision.
- Covid & Brexit have contributed to the general workforce shortage. In this current financial climate, social care roles are not always very attractive, particularly in the third sector.

## Are there obstacles, facilitators you can identify for those who have transitioned, or are transitioning?

- Starting with the needs, wishes, and hopes of the person being supported is essential; always trying to remember it's their life being planned, not just a 'service'.
- Remembering that family (where present) are an essential part of the process, and that they have generally known the person all their life, and care about them more than we ever can. So we need to listen to them.
- Good communication and partnerships between everyone involved are essential. And it's really obvious to say, but health & social care need to work closely with together; that doesn't always happen.
- Rushing a transition, e.g. from out-of-area placement to somewhere nearer home, means that there isn't sufficient time for staff to really get to know the person (and vice versa). This means staff don't have opportunity learn how the person communicates, to know the best ways to respond in different situations, to feel confident and competent in their support; this can unintentionally set a placement up to fail.
- A suitable house, with the right adaptations, the necessary space, accessibility to the local community, makes a huge difference to delivering successful support.
- The social care provider needs staff who have a good understanding of complex support needs and in particular in relation to behaviours that challenge. Positive Behaviour Support is a key element of developing the right support. This needs to be augmented with Practice Leadership, i.e. good quality, practice-based support to staff in their day-to-day work.
- If a person goes into hospital and loses their placement, it is much more difficult for them to leave hospital when they are ready. Keeping service placements open, and continuing to fund social care providers for this, could reduce delayed discharges significantly.

**Five years later, with Appletree established and Louis having lived there for year, Kate writes:**

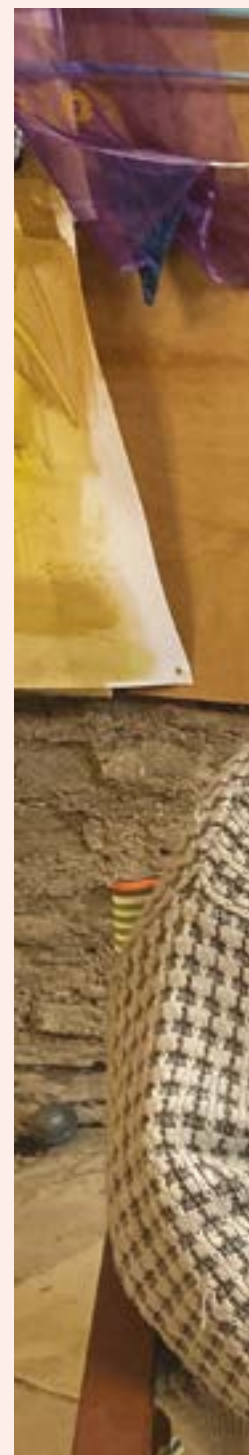
The central understanding I seek in Appletree is that Louis is equal to anybody else in this world, that he is a human being like everybody else, feels things as others do, has human emotions like everybody else, loves, hopes, fears, remembers, looks forward to happy events, feels sadness and remorse.

It means that he should be included in conversations, his views taken into account, he should be supported to do as much for himself as he can, rather than being disempowered to become a passive recipient of care. Seeing Louis as human means he should be treated with respect, as an adult man with gifts and skills, at the same time as acknowledging he needs help.

I seek it to be understood that Louis is vulnerable, that he is medically traumatised in addition to his underlying brain injuries and that he needs safety, reassurance, compassion and kindness in all interactions with him, a 'Low-stress environment'.

I seek a commitment that physical violence should not be used against Louis. I seek an understanding of Louis's behaviours that some are manifestations of a history where people have used force rather than understanding, thereby damaging him and making him afraid.

Pastoral visit from the Reverend Charles















Louis doing Bookbags with Jane, one of the Trustees of the Apple Tree Trust

I seek the development of a goal of shared happiness for Louis, his care team, his friends and community.

Part of the reassurance Louis requires is a regular pattern of activities, from which he can orientate himself to what is happening next and when.

Louis requires the development of communication skills within his care team and his community. That means us who are not Louis need to learn to speak his language and understand what he is saying, for the pleasure of two-way interactions. It means sharing mutual communication like songs, music, familiar rituals, and practices. It means using photographs and visual symbols to give Louis information about his day, as an alternative to words. It means developing the capacity to tell stories together, to remember happy times, to look forward to pleasurable times ahead. It means recognising Louis's capacity for and enjoyment of storytelling, his fantastic memory, his wide circle of friends and places familiar to him, his enjoyment of and skills at swimming, cycling, trampolining, painting, letter-writing, hospitality, singing.

It means recognising Louis's innate generosity and willingness to forgive, to put unhappy memories behind him and to start each day afresh, with optimism. It does not negate the store of unhappy memories that trigger trauma responses in Louis over which he has no control, but which, together as a community, we can all commit to overcoming, through our love and commitment and care for one another.

## LOUIS'S VOCABULARY

These are words that Louis uses and the list is not exhaustive. I estimate I have recorded about three quarters of the words he uses.

*Familiar phrases used by Louis and others including greetings*

Look  
 Bye bye house  
 Ring them up  
 A letter for Mum  
 Are we ready  
 Not just now  
 Would  
 A present  
 Happy birthday  
 Ring the bell  
 The telephone  
 Whose  
 Tomorrow  
 No  
 Yup  
 A letter well done  
 And  
 We're off  
 Good morning  
 And

well done everybody

Happy Christmas what?

The next birthday

bye

yes

listen

you like a cup of tea?

goodbye

night night

it's gone

is it?

come in

Easter

other day

it's shut

it's hurting

ew's birthday, daisy's birthday ...

*Activities including swimming,  
trampolining, walking, letter writing*

The music on

Felt Pen

pen

Stamp

window

Running

put the music on

TV

RO

bicycle

bus

walk

ball

paper

Trunks

winky winky

La-La

ball-pool

A big bus

Trampoline

dipsy

Msey Rapids

Teletubbies

po

another bus

**PART  
TWO**

### Reflections that arise from Kate's love for Louis:

- Love is a revelation of its own integrity. This Mother's love is incarnate-intrinsic. It just is, and her recognition of the love for her from her child.
- It is through this love, nurturance and affirmation that we who are not Louis or Kate enter into their experience with an invitation to share love and be loved through creativity and radical hospitality.
- Their lived experience is the founding gift for a community based on inclusion. This inclusion redeems cycles of societal exclusion and violence through their forgiveness as victims rather than a demand for retribution.
- How do Louis and Kate engage in the co-creation of a loving community releasing the potential energy of relationships to create a good life for Louis in a good society that is good for everyone?



## MAUREEN PHILLIP

Practice Development and Inclusive Culture Programme Director. [PAMIS \(Promoting A More Inclusive Society\)](#)

[Link to website](#)

The Kawa Model and the metaphor of the river holds my story and is told from my perspective. It captures my reflections in this piece of writing. I found the reflective writing therapeutic from the point of view of enabling me to process all of my experiences on this journey. I wrote a very long and very personal reflective piece about every aspect of the journey I am on with Louis and Kate. Using the river as my guide I charted every barrier and blockage that prevented the river from flowing as it should. It was a roller coaster of emotions, but for the purpose of this research I have condensed my reflections considerably.

This is a personal reflection of my story journey and where it joined Louis stories. It is a personal account of what this journey has revealed for me and what Louis has taught me along the way. I say Louis stories because for me Louis has his own story but he also has to cope with the stories of each and every person who touches his life. Each of these stories weave themselves with Louis story and they have to be navigated by him through rough seas and smooth. It is a journey where stories intertwine with each other and where Louis and everyone involved in his life has to navigate new ways of being. For me Louis story is one of adversity, bravery, challenge and hope. It is at times extremely sad and in all honesty, what has happened to Louis on his journey to live his best possible life is unforgivable but what Louis story clearly reveals is that it is time for change in practices. As a society we have to now admit that Louis story demonstrates that our health and social care systems are broken and do not adequately provide what is required for people with profound and multiple learning disabilities to live a good life, which is all they want to do.

Louis has endured a lot and his story reveals systemic failures of “systems” that need to change, not only for Louis but for his family and those that care for him. When I refer to systems in this reflection, I am not referring to the people who work within the “systems”, I am talking about the wider structures and values that reflect the system as a whole, how it is managed as well as how policies, procedures and practices are implemented. I know those working within the “systems” are just as constrained and frustrated as Louis. I would also like to say that I am reflecting on my personal journey with Louis story from a social justice and human rights perspective based on the charter of storytelling rights that was developed by David Denborough.

## The Charter of Storytelling Rights – David Denborough

### **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.

### **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, honoured, 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.

*By claiming these rights we give ourselves permission to be the ultimate authority on our own life and experiences. As soon as this occurs, we can begin to tell and retell the stories that define who we are and how we relate to the world around us.*

(Denborough, 2015)

Sitting by the riverbank, listening to the river ripple over the stones I reflect on Louis story and how sad it is that he has had to endure what has been a traumatic and at times terrifying journey, inflicted on him by the very services that are supposed to nurture and care for him. I have been present at local policy meetings and listened to the plans, proposals and praise of services and what they are doing but then I see the reality in practice and wonder what goes wrong in the translation of policy into practice. For me actions speak louder than words and before me I see the result of broken promises and hollow words. I see Louis often, sad and unhappy, broken by the very systems that are meant to be there to support and care for him. I see the direct impact of service provision that I would say, has lost its way. Services whose language is the language of institutionalisation, often managed and delivered by people who are not specialised or have the necessary knowledge, skills or support to provide the level of care and understanding that is required to properly enable someone with profound disabilities to live their best possible life. It is important for me to include my personal reflection here as it is my story and from my perspective what my story reveals to me is; that beneath what I see as the veneer of policy, strategy and frameworks is that there are hidden stories that need to be heard. It is the right of every person to have their story heard, witnessed, and honoured. People with profound and multiple learning disabilities are marginalised and their voices are not heard. These are the hidden stories that are forgotten yet these are the voices that teach so much. They teach care, understanding, trust, devotion, love, hope and so much more. For me that is what this mother's vision and her son's story does. It reveals the hidden stories, the unheard voices of people who do not have a voice. It unveils how the system functions believing in the illusion that what they are providing is person centred care. There is nothing person centred about services or commissioning of services that fail to provide specialist



help from allied health professionals to support struggling care staff. This is not a criticism of service provision, as the people working in health and social care have their stories too and often these stories are unheard and hidden beneath the veneer too. This is my personal perspective and reflection, based on what I see in practice every single day. As a society we like to think we are creating a better world for the most vulnerable in our communities and in some ways we have come a long way but unfortunately there is a long way to go.

Until we unveil the hidden stories that have a right to be heard, and acknowledge the reality of what is required to provide true person centred care for everyone no matter their disabilities, we will be doing an injustice to many and inflicting ongoing unnecessary trauma on people, while all the while believing that person centred care is what is being delivered. Louis is one story but he is the voice for many and we all need to listen to him and honour his story. His story is the narrative of the change that needs to happen for him and for everyone else whose story remains hidden from view. The river is the perfect metaphor for my story journey with Louis and his mother's vision of the future for him. My story is a tributary that joins Louis river as a supporter to him and his family. It was and still is a journey fraught with many barriers over many years. From the vision to its implementation and sustainability, the journey with Louis and his family has been filled with barriers too numerous to mention in a reflection.

At first my story joined Kate's story. She was the first inspirer and she introduced me to Louis story and I found myself in Louis river. I joined Louis river at a difficult time as he was being evicted from his long term home with nowhere to go. It was a traumatic time where Louis was let down by a system with no provision for him in his local community and he was at risk of being placed out of area. Unfortunately, eventually,

Louis was placed out of area and a journey of upset and trauma began for him. Not only had he lost his home but he lost his community. At this point my reflection turns to community inclusion. Inclusion is something that is spoken about a lot in terms of people who are socially excluded in society and often it is spoken about in terms of physical access or being part of a group, without even considering whether the group is appropriate or what it means to someone to be a part of a particular group or activity. Inclusion is more than that, inclusion is a state of feeling valued, respected, and supported appropriately. Community too is not only a place to live but a place to feel a part of life and of society, of feeling wanted, valued and a part of life in the community. Louis has a community around him and in time that community will grow and flourish. His community is a place where he is valued and accepted for who he is. When someone is uprooted and moved from a community and people they know there is a trauma attached to that if it is not adequately explained and supported. Again, I reflect on the fact that the term community inclusion is often misinterpreted and the gap between how it is described in policy and put into practice is vast but that requires a paper on its own and is deeper than my reflection can convey. For me, knowing that Louis is safe, understood, and participates in activities that are purposeful and meaningful to him in his own home and community in a way that is relevant to him is all that he requires to live a good life. Is that really too much to ask?

## My reflections turn full circle back to the vision.

The birth of this vision is a light of hope for the future that needs to be built on understanding, trust, honesty, love, kindness, respect and it has to be a vision of togetherness. There is still much to do in this river of implementation and sustainability and there are still boulders to navigate but there is driftwood and a reasonably stable river bank will hopefully support this part of the river. It is the families of people with profound and multiple learning disabilities who are experts by experience, and it is only by everyone working together and listening to the voices of those who struggle to be understood that we will become better at really hearing their voices. Their stories are hidden and misunderstood by so many. We owe it to them to show we care enough to listen, hear, acknowledge and let them tell their stories. They have much to teach society about what it is to be human, and to care - we have to listen. It is time to put compassion into policy and meaningfully put policy into practice. Appletree is a vision of love and hope and it is time for the vision to shine.

Dear Aaron

Kate and I are wondering whether there could be scope for your institute (yourself?) and for the Quality of Life and Wellbeing Research Group in your Dept of Psychology to be involved in a piece of 'accompanying research' about the development of Appletree, including appreciative evaluation.

Karl Nunkoosing and Mark Haydon-Laurelut wrote *The relational basis of empowerment: the power of Acceptance and Hope*, in the *Need for Roots* series (recalling Simone Weil), about autism. We are wondering if there could be a synergy here for us and within Portsmouth.

We would clearly need to get some funding. This could tap into your phenomenological approach and your interest in peacemaking.

We would be glad to discuss this with you.

All the best

Rob Mackay

Chaplain to Appletree

Dear Kate, Louis and Rob,

Happy New Year to you and your families and I hope that you managed to have some relaxation over the Christmas period.

Kate, first, I feel it important to include Louis in all communications as an equal partner in this project, and second, I have started to properly read and immerse myself in the material that you have sent me to try and make sense of yours and Louis's lived experience. What is emerging for me is a rich and powerful testament to the embodiment of suffering (personal experiences that are also representative of the "whole system"), and struggle but also hope for and actualization of change. From this reading then a number of questions are starting to emerge which I

would like to discuss with you further to really get an orientation on the research project, its focus and what you would like the outcomes to be. This will help to refine the research questions, the most appropriate methodology, who needs to be involved etc.

Through intuition and empathy, I would like to try and articulate research questions which explore the spaces “between” (spaces of creativity - the domain of the Holy Spirit) individuals and organisations, care and control (coercion), the clinical and the spiritual, choice and finances (there will be plenty of others) to resolve intractable problems.

This will give the project a peace-making orientation.

Best wishes

Aaron

Dear Aaron

Happy New Year to you too. Thank you for your greetings to us.

Thank you, also, for your intention always to include Louis in communications as an equal partner.

Related to that and pointing forwards to our future means of communicating, I am delighted to tell you

that Louis has had his first zoom meeting as Co-Chair of the Scottish Commission for People with Learning Disabilities Advisory Group on Human Rights. Louis was invited to take

up this post, with a very clear intention that by including Louis in group work, his very presence would benefit everybody's awareness and approach to matters in hand.

Louis, another Co-chair and the Lead from SCLD, plus me, met on Friday.

We built up confidence in our ability to communicate through zoom, and trust in each other as partners we wanted to work with.

Best wishes

Kate and Louis



# DEVELOPING RESEARCH

Methodologically,

in order to build a relationship between Louis and

Aaron, we chose zoom as a way of meeting,

familiar to Louis

through his engagement on zoom with SCLD.

Louis's reaction to Kate's explanation about meeting Aaron was to talk

about his favourite food Lasagne. In response Aaron produced

- and shared -



# SEARCH RELATIONSHIPS



photos of Lasagne and his favourite food Shepherd's Pie.

Our first meeting was about being with each other,

looking at the photos,

enjoying the moment.

We who are not Louis are holding open the possibilities of the meanings in Louis's contribution as a research partner.

**Aaron asked a question:**

Are those foods suggested by Louis as benchmarks of pleasure in the interactions/ his agreement and comfort at the tone of our whole-group collaboration?

'Yes, this is possible. The familiarity and delight of food is so central to Louis's experience, we know he has a great store of sensory food memories, associated with powerful, positive emotional experiences. If we agree this is Louis's meaning, we are attributing to him the power to make metaphors, a key human linguistic and epistemological capacity. We can see in a verse in Psalm 34

**Kate replied:**

*'Taste and see that the Lord is good, happy are they who trust in him!'* a similar link is made between the evocation of the delight of food and the goodness of God:  
4/05/23

**Aaron asked:** Are they suggestions of happy memories?  
Or plans for the future?

'Part of the pleasure of food is exactly that it has a quality of reliability. In Louis's experience food functions both to remind of good times already known and to anticipate good times ahead.'

**Kate replied:**

Methodologically, we who are not Louis are holding open the possibilities of the meanings in Louis's contribution as a research partner.

We who are not Louis have learned from Louis. He reminds us of how concrete we need to be in planning .. and enjoying .. and communicating.

He reminds us of the need to go on being curious, to go on being open to possibilities, seeking feedback as we go, celebrating common understanding when we reach it...

**Kate:**

What was also positive was that Louis really enjoyed engaging, being part of a community with a task and a focus, especially when he could hear that it was all about him.

Going back to the initial stage of inquiry, in an exchange of messages, **Kate responded** to Aaron with the following :

I welcomed the forward-looking approach that is towards hoping and actualising change.  
I welcomed your intuition of exploring spaces 'between' as you say '(spaces of creativity - the domain of the Holy Spirit)' as a means of giving the project a peace-making orientation.

In line with that,  
I notice that where in my pursuit of the planning of Appletree, I have personally changed my language towards a 'please can you help here' approach - away from a 'here's the problem' diagnosis, the request for help becomes an invitation to others to join in and take ownership of the problem, to work collaboratively with me towards solutions.

That identifies some values -  
of collaboration, levelling of power, openness, recognition of all people's experience - that are needed in order to build a community that is problem-focused, hopeful, effective.

Louis has brought together the following people as part of the research team

### THE APPLETREE TEAM

Appletree

Louis Sainsbury

Kate Sainsbury

PAMIS – Promoting a More Inclusive Society

Maureen Phillip

### UNIVERSITY OF PORTSMOUTH

Dr Aaron Pycroft,  
School of Criminology and  
Criminal Justice

Dr Karl Nunkoosing,  
Department of Psychology

### EDINBURGH NAPIER UNIVERSITY

Dr Michael Wamposzyc,  
School of Arts and Creative Industries

Dr Natasha Spassiani,  
School of Health and Social Care

Sam Abdulla,  
School of Health and Social Care

Leo Philp,  
School of Arts and Creative Industries

Imogen Grieve,  
Graphic Designer

## **PARTICIPANTS IN THE Kawa RESEARCH DAY**

Marian Gerry, community supporter

Jan and John Southorn,  
Appletree prayer group

Zoe Robertson, Interim Head of Adult Social  
Work/Social Care & Service Manager for  
Commissioning and Policy, Perth & Kinross HSCP

Jacquie Pepper,  
Chief Officer Integrated Joint Board

Jenny Miller, CEO PAMIS

Councillor Colin Stewart, Vice Chair Integrated  
Joint Board, present as an observer.

## **OTHER CONTRIBUTORS TO THE RESEARCH**

Dr Anne Macdonald,  
University of Glasgow

Nick Wharton, Aiteal Trust

Marie Todd MSP



Maureen Phillip from PAMIS introduced us to the Kawa approach which proved to be very powerful in developing the story of Appletree

### The Kawa Model

Professor Michael Iwana is the originator of the Kawa “River” model.

The Kawa Model is an Occupational Therapy model that uses the metaphor of a river to explore a persons life circumstances, and problems in life.  
It supports ways to help navigate and improve their everyday life or circumstances.

The Kawa Model is a conceptual framework that helps individuals to understand their unique life perspectives and how their environment impacts their daily activities.

It emphasises cultural sensitivity and consists of three components:  
barriers,  
social/ physical environment,  
and strengths/ supports.

The model is useful for learning more about an individual's history, overcoming barriers and identifying goals to improve their quality of life.

The model recognizes that a person's experiences and identity shapes their understanding of their past, present, and future.

When using the Kawa Model to explore someone's history, the person is central in the river, with their past experiences represented by the objects within the river.

By examining these objects, the person can reflect on their past experiences and how they have shaped their current situation.

By acknowledging the factors that impact a person's life, you are able to help build trust

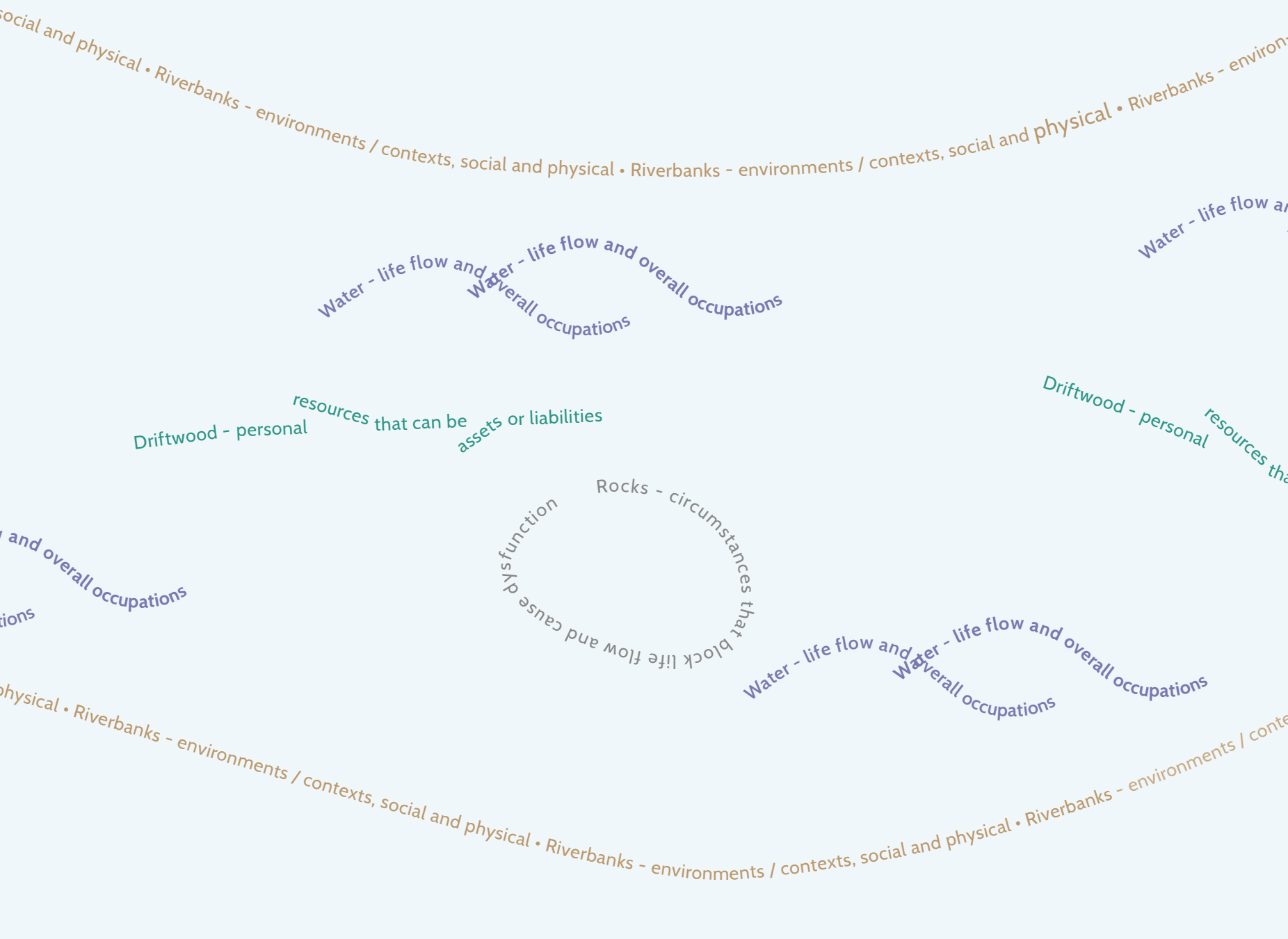
and rapport with the individual you are working with.

This allows a deeper understanding of the person's experiences and leads to more effective strategies to promote their well-being.

# HOW TO USE THE



# THE KAWA MODEL



# 1.

Start by introducing the Kawa Model to the family and the person you are creating the story for, explaining its components: barriers, social / physical environment, and strengths / supports.

# 2.

Engage in a collaborative discussion with the everyone to understand their unique perspective on their life and health. Encourage them to share their goals, values, and life history.

# 3.

Visualise the person's situation using the Kawa Model. Use the river diagram provided and use the banks to represent the person's environment. Have the person as the central focus of the river. Use the rocks to represent barriers and the driftwood to represent strengths, goals and support already in place. Write any extra notes corresponding to the numbered objects on an attached document.

## 4.

Work with the family to identify the barriers and facilitators in their environment that impact their life. Encourage the person to express their concerns and feelings about their situation.

## 5.

Collaboratively develop a plan with the person that incorporates their goals, values, and cultural background. Use the Kawa Model to visualise the plan and ensure that it aligns with the person's unique perspective.

## 6.

Evaluate the plan's effectiveness regularly with the person and make adjustments as necessary. Use the Kawa Model to visualise progress and identify areas that may require additional support or modifications.

## 7.

Celebrate successes and encourage the person to continue working towards their goals using the Kawa Model as a guide.



## The Kawa Model-A Journey of Exploration along the Appletree River

### Why the Kawa Model?

If you follow a river from source to sea you will find lots of stories along the way.

Stories in the land,  
of the natural habitat around the river and off course  
stories of the people who live along the rivers route as it flows along.  
Some parts of the river flow slowly across rocks and stones,  
others can be more fast flowing and with deep dark pools in places.

The river has seen stories through the ages too.

Like the river the stories in our lives sometimes  
ebb and flow with happy and sad times,  
with ups and downs,  
with dark deep pools that rumble and groan across rocks and boulders.

Just as the river begins as a source,  
so do we.

The river grows as it makes it's way through the landscape,  
so do we.

Tributaries also join the river as it makes it's way through  
the landscape and each of these tributaries have their own story.

Like the tributaries that join the river we have people that enter our lives  
and they bring with them their own stories.

These stories interact with our personal stories  
and then our story changes and evolves.

Stories connect people and communities

and the story of Louis journey has not always flowed easily  
and has been impacted by the stories of others along the way.

The Kawa model enables Louis life story to be heard,  
witnessed, honoured and be known and understood by those who are caring for him.

It also enables the stories of those involved in his life to be heard and understood.  
It supports an exploration of the stories of both the barriers

and the enablers in his life as well as the environments that like the riverbanks,  
have held him, both as strong,

places of safety and also places where,

when safety crumbled he has felt like a prisoner.

The Kawa Model supports the story of Louis journey,  
his families journey and their vision  
and all whose stories have intertwined with Louis story.

The journey along the Appletree River  
is a journey of hope for Louis  
and for the future of care for everyone.



Research Day at the Bioid







Research Day at the Biold







Research Day at the Field

Continuing the research narrative  
and how Louis engaged with us,

*much later,*

in April 23, we met for a Research session at Appletree, when Louis welcomed academic researchers, the storyteller from PAMIS and his mother, into his own living space. Using the Kawa model of storytelling, we spread a roll of brown paper on Louis's living room table, which is where Louis regularly writes letters and draws (this letter writing uniting Louis's emotional drive and his creative and intellectual interests).









Research Day at the Bield

The paper had a pre-drawn river design giving a 'directional flow' to the paper from one end of the table to the other. Louis was encouraged to talk about his own life story, things meaningful for him, what makes and has made him happy, what he looks forward to. Louis and we were using words together,

we had available felt pens for drawing,

stickers to choose and attach,

as well as the overall position

on the paper to show the progress of time.



Research Day at Appletree







Research Day at Appletree



Research Day at Appletree



Baby

Louis  
Loves  
balloons

Louis  
Loves  
balloons

Louis  
Loves  
balloons

Cake

DAN

MIRTY

Envelope





Research Day at Appletree



To begin with,  
*Louis was a bit shy,  
having greeted everybody,*

he cut out too much stimulation by sitting with his back to the room where others were seated. His mother and the storyteller, along with one researcher, sat round the table with him. When his mother asked if he wanted to change seats, so he could see more of the group, he acknowledged the question in a friendly way, by turning round to look and smile, before he turned back to the task, where his choice was obviously better for him.



Research Day at AppleTree



Research Day at Appletree









Louis really enjoyed the task.

He used many concrete words,

*drawings,*

*stickers,*

he smiled and he spoke very energetically, he rocked on his chair in an expression of contentment and happiness. Within the task, Louis interacted with his mother on the story telling about his life so far, but what really motivated him was thinking towards the future, volunteering words about things he looks forward to. He did not speak about hardships he has experienced, he looked forward to those things that give him pleasure. He was particularly focused on having a summer holiday, using the word 'Appledore', a coastal village in Devon known to Louis, to mean summer holiday, sunshine, swimming in the sea, *family time,*

*being with mum,*

*meeting lifelong friends.*

Research Day at Appletree - Photo taken by Louis







PART

THREE

## **The Key Messages Emerging from the Research**

Telling a story about people

# VISION

The fundamental vision was to create a community where Louis and the people caring for him felt safe and supported, surrounded by beauty to lift spirits, with opportunities on site for active, meaningful days, and connections with wider society for both Louis and staff.

## Rocks / Blockage

Rocks - circumstances that block life flow and cause dysfunction

• NEED TO RECRUIT AND TRAIN A TEAM OF NINE/TEN CARERS TO SUPPORT LOUIS 2:1, DAY AND NIGHT • NEED TO RECRUIT AND TRAIN A TEAM OF NINE/TEN CARERS TO SUPPORT LOUIS 2:1, DAY AND NIGHT

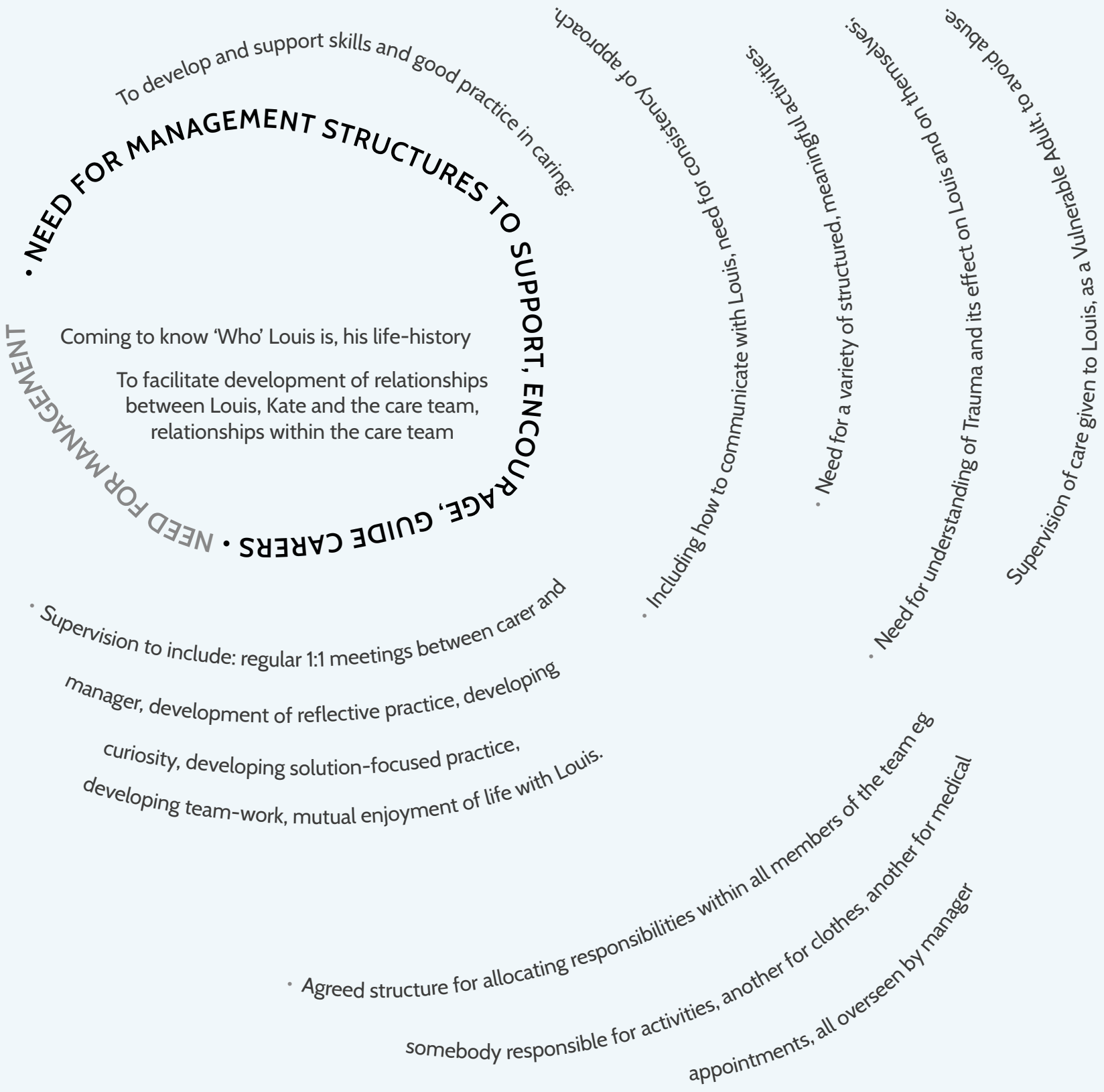
Need to recruit people of integrity, kindness, desire, responsibility, fun, various gifts, to meet Louis's needs for quality care in his own home

Challenge of recruiting carers in wider societal context without agreed graduate or any other training pathway for carers, where low rates of pay do not attract people to care

Need for initial and ongoing training for carers, to match their gifts with Louis's needs.

Training to come from various sources:

- Louis himself.
- Kate (lifelong experience of Louis, and vision of Appletree)
- Allied health professionals: Occupational Therapy, Speech and Language Therapy, clinical psychology.
- In-house care provider's own training resources.
- Support organisations eg PAMIS (charity supporting people with PMLD) for digital passport.









People 'see' the disability and not the person. Lack of positive images of people with PMLD, like Louis, in society, in the arts, in community life.

There are varied professional and personal interpretations of expectations of Louis and people like him enjoying their best life through being able to leave home and live independently. How they vary differs from area to area, organisation to organisation.

Public and third sector organisations, may only pay lip-service to 'person centred care', often failing to understand real inclusion, the right to choose where somebody wants to live, who with, who cares for him, what he does for meaning and purpose.

• ABSENCE OF ENABLIST VALUES

• ABSENCE OF ENABLIST VALUES AND BEHAVIOURS ACROSS THE SYSTEM AND SOCIETY

**CARE TO HIGH STANDARDS**  
**• ORGANISATIONAL ARRANGEMENTS FOR COMMISSIONING HINDER PARENTS AS ACTIVE PARTNERS IN ARRANGING/MANAGING CARE TO HIGH STANDARDS**

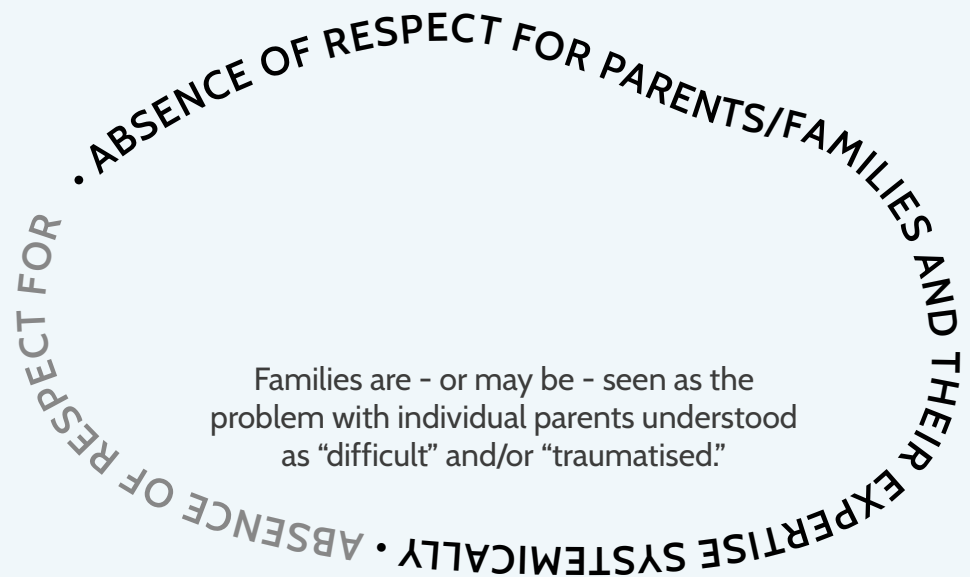
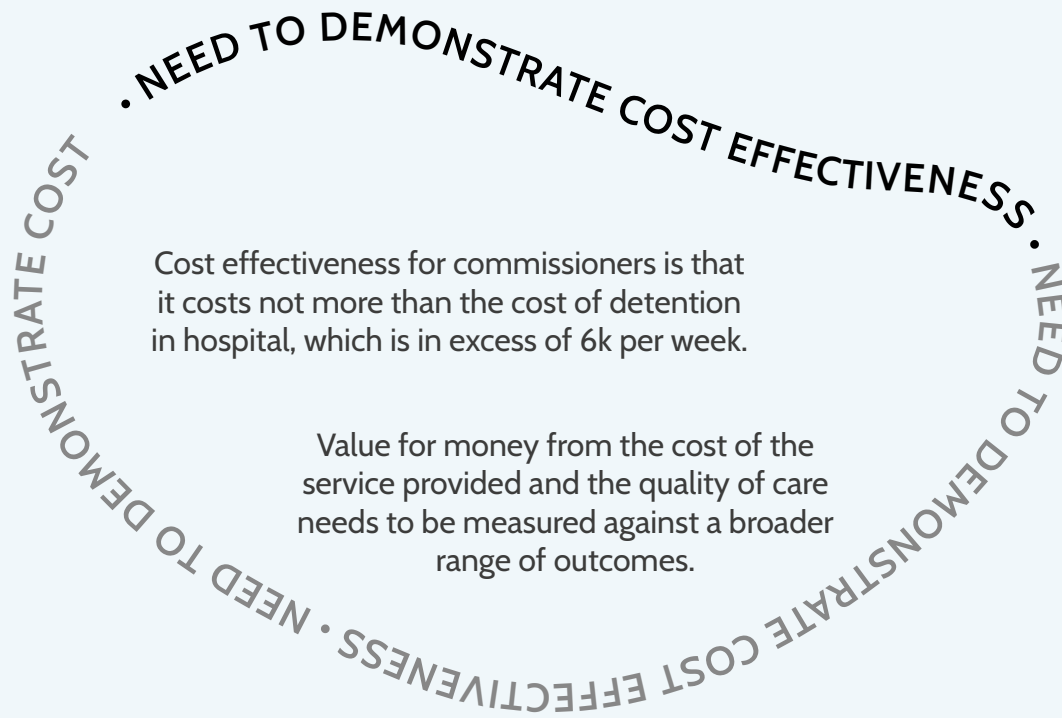
Despite the rhetoric, genuine choice for parents to ensure high standards of care is prevented through economics, as self-directed support has an annual budget limit that does not cover the costs of somebody with high care needs, like Louis.

This means that Louis and others in his situation are dependent upon the local authority to commission care provided by either private or third sector organisations where the family/ Welfare Guardian has little control over quality of service delivery.

Local authority care commissioners have a lack of understanding of Self Directed Support implementation and shortcomings as experienced by Louis and his mother, and other families.

Families' expectations of 'professional services' vary. Given the reluctance of families to approach to ask for the funding/resources they actually need this is a major barrier.

While you need people who understand the challenges to be in post, this shouldn't be dependent on a particular person, but on human rights and enablist values







## Driftwood / Moving Forward

Driftwood - personal resources that can be assets or liabilities

Kate, with support from PAMIS, established steering group as a study/research group to drive forward support for the vision in the local authority and wider.

### Gaining practical and political support for the vision

A civil servant from Scottish Government's learning disabilities team, joined it, brought in CEO of Housing Options in Edinburgh, and Dr Anne MacDonald University of Glasgow and adviser to Scottish Government.

Perth and Kinross Council were better-disposed towards the project through previous good experience of working with a parent-driven project, parent-led purchase of property for care

PAMIS existed as support organisation for people and their families with PMLD to accompany Kate

Kate's faith:

Kate's faith that pursuing the vision of Appletree was an expression of her faith, in a God of Love and Justice and Community, who was calling her to do this. Her belief that Appletree might benefit others. Her faith in the principle of collaboration, the power of love, the vision of a long-term home where Louis could settle down to recover from his traumatic past, to flourish. Her faith that what she was doing was in a sense, 'God through her'.

Kate's faith in Louis as a person, as somebody who tells the truth, who never fabricates, who enjoys life and enjoys good relationships if he feels safe, has purpose, orderliness, nice things to look forward to, content with little, if he receives kind attention.

Kate's faith gave her the strength, courage, tenacity, to keep going through all the hardships, setbacks, disappointments, fears, betrayals, challenges that she met on the way.

Kate's faith in people, in community, who care about Louis and people like him, needing homes; faith in society believing in Justice, Human Rights, Love, Inclusion of the weak, the two-way benefit of this.

Kate's faith that Love triumphs challenges her to be a peacemaker, even in the face of harm to Louis

*Assets of faith*

Prayer - and Love - and application of energy - was Kate's means of pursuing this project.

Louis's faith:

That the stories his mum told him about leaving hospital, going to live in his own home, were going to happen 'one day' - even when waiting was hard, helping him keep hope alive in dark times of oppression. Louis's faith was influenced by his knowledge of Kate's love for him.

Louis will have struggled to reconcile Kate's love for him and the bad experiences he nevertheless suffered, when he will have wondered why she let those bad things happen.

Prayer for Louis was a reminder that he is Loved, that there is a bigger timescale.

Other people's faith in Kate to carry this vision through.

Her demonstration of her capacity and determination by the purchase of the buildings

The award of the Alastair Haggart Fellowship from the Scottish Episcopal Church for the exploration of Appletree as an intentional community and alternative way of being Church, gave Kate belief in the project and herself to lead it

### Physical assets of Appletree

Kate's capacity and plan to purchase Maidenplain Steading gave a physical reality to the vision.

### Academic support for the model

Academic evidence upholding and supporting the vision of Appletree, importance of Relationships, Hope, long-term commitment in care staff eg Nunkoosing and Haydon-Laurelut 'The Relational Basis of Empowerment'; Rev William C Gaventa, 'Disability and Spirituality' speaks about the importance of commitment in caring relationships.

## Existence of models of community

care provision to learn from

eg The ethos of a children's hospice where people are helped to feel safe, Norlands nanny training

Parents who had established homes for their adult children.

Camphill, l'Arche communities who support people with LD, with moderate learning disabilities

Appletree envisioned Appletree as separate from her family home, Louis supported full-time by carers, requiring quality 'family-style' relationships between Louis and carers eg eating together, enjoying activities together, with regular time with herself and Louis and staff members

## Assets of Kate's background to pursue project

Kate's love for Louis, her desire to create a long-term home beyond her own life

Kate's professional experience and training in social entrepreneurship, Public Involvement, Project Management as Arts Manager and Publisher, Lay Readership in the Church -

of others, her spiritual training and role within wider church and society

Organisations to do with advocating, motivation and commitment, with making things happen for the benefit

Assets of Kate's wide network of societal relationships and community networks, locally, nationally, internationally

## *Assets of professional attitudes towards working with families*

Learning Disabilities policies at local and national levels encouraged this

Professional understanding of family dynamics, what it takes to support someone like Louis in the system that we have.

## *Assets of Louis's financial security*

Louis's eligibility for benefits for living expenses was already established

Court-held funds were a source of capital to purchase house



## Water / What is the energy to move this forward

There was no alternative! Louis desperately needed a future where he could live and be cared for, alternatives already tried had failed, hospital was not an answer.

Loving Louis

Support from Maureen Phillips at PAMIS

Knowing Louis had had a rich life

Joy Faith Justice

Family commitment love

Systemic thinking

Knowing Louis has had a good care in his previous care placement

Family life "holding" Louis

Human Rights Framework

Louis experience of range of activities and capacity to enjoy life

Reference to Scottish policy documents on Learning Disabilities

Nothing to lose and everything to gain and with curiosity at organisational and personal level as to whether a new model of care could work for somebody with high care needs for whom there had previously been no solution in the community.

Capacity to live with uncertainty, looking to the future with hope

Capacity to see with new eyes

May it be a house of courage,  
 Where healing and growth are loved,  
 Where dignity and forgiveness prevail;  
 A home where patience of spirit is prized,  
 And the sight of the destination is never lost.  
 Though the journey be difficult and slow,  
 May there be great delight around this hearth,  
 May it be a house of welcome  
 For the broken and diminished.  
 May you have the eyes to see  
 That no visitor arrives without a gift  
 And no guest leaves without a blessing.

From a blessing 'for a new home' by the late John O'Donohue, from 'Benedictus' published 2007 by Bantam Press

# IMPLEMENTATION

## Rocks / Blockage

Rocks - circumstances that block life flow and cause dysfunction

### Timeline:

Kate as Deputy applied to the High Court for an Order authorising purchase of property. Applied December 2017 - Court Order granted August 2018.

Suitable property identified June 2019. Kate ensured Key stakeholders agreed as to suitability. Purchased October 2019.

Delay until confirmation of care-funding came, August 2020, before commissioning architect for adaptations required, tendering for works required.

Work schedule decided October 2020. Building works started December 2020, finished June 2021.

CHALLENGES OF TIME • CHALLENGES OF TIME • CHALLENGES OF TIME • CHALLENGES OF TIME • CHALLENGES OF TIME

Waiting for agreement for housing

• WAITING FOR AGREEMENT FOR CARE •

Time taken to effect collaboration between the stakeholders - parent, local authority and care provider- Kate coming to be understood as a key partner, with a positive contribution to make, for agreement on the vision of Appletree.

• WAITING FOR AGREEMENT

Timeline:

Multidisciplinary agreement to Vision agreed late summer 2019.

Decision-making over choice of care-provider and funding costs of care agreed August 2020

WAITING FOR ARRANGEMENTS WITH CHOSEN CARE PROVIDER FOR PROVISION OF CARE • WAITING FOR

Timeline:

Contract for care issued to care organisation August 2020

Manager selected by care organisation in-house (no choice for Kate) October/November 2020

Two Key Workers recruited end 2020. Started working with Louis and Kate in hospital Feb 2021

Three more care staff started March 2021

First overnight visit to Appletree June 21. Second overnight July 21, gradually building up, to 2 nights, then up to 5 nights/week October 21.

Still insufficient numbers of staff to cover rota for Louis to be discharged

Discharge from hospital May 2022



• WAITING FOR RELATIONSHIPS AND SKILLS WITHIN CARE TEAM TO DEVELOP •

Time needed to develop skills and confidence within care team members, to understand Louis's vocal communication, his behavioural communication, to know who he is, how to care for him physically, how to support his stress-responses, for the staff team to learn to cook, to develop household routines, to know his and his family's stories

• WAITING FOR RELATIONSHIPS AND SKILLS

• LOUIS WAITING IN HOSPITAL, JEOPARDISING HIS WELL-BEING •

Lack of planned activities, boredom, ineffective communication with staff, restraint, dependence on visits 4 - 5 days a week from mother, occasional visits from friends. Initial phase Jan 2019 - Feb 2021 in Carseview, LDAU, Ninewells Hospital. Moved Feb 2021 to Strathmartine Hospital. Remained there until discharge May 2022.

• LOUIS WAITING IN HOSPITAL, JEOPARDISING HIS WELL-BEING •



• RISK OF FRAGMENTED SERVICE DELIVERY •  
• RISK OF FRAGMENTED SERVICE DELIVERY •

Silo- working across health and social care and 3rd sector organisations

Health and Social Care Partnership input into Appletree after implementation that should guarantee

quality of service through the contract with the care provider was hard for Kate to access

Community mental health provision that should ensure input from allied health

professionals' to support staff and Louis took time to establish

Lack of input from allied health professionals to care team held up the establishment of meaningful

activities, guidance on how to engage with Louis, access to equipment, understanding of benefits

of occupational therapy and speech and language therapy



• EMPLOYMENT CHALLENGES • EMPLOYMENT CHALLENGES • EMPLOYMENT CHALLENGES

Lack of recognition of what a skilled job is entailed in caring for Louis

Lack of specialist care skills required was a national and local issue, post Brexit, post Covid

Low carer pay £10.90 per hour insufficient for recruiting and retaining staff

Rural/Semi rural settings were said to be a barrier to staff recruitment and service provision, though Appletree is within 400 yards of a major arterial trunk road and a regular bus route

Despite policy rhetoric Louis has no choice over who cares for him.

In the context of organisation's challenges to recruit any staff, there was no scope for Louis to exercise choice or preference

In the context of organisation's challenges to recruit any staff, there was no scope for Louis to exercise choice or preference





• LOUIS'S UNHAPPY EXPERIENCE OF HOSPITAL • LOUIS'S UNHAPPY EXPERIENCE OF HOSPITAL •

Continued throughout his transition from his first overnight stay at Appletree June 21<sup>st</sup> to discharge May 22<sup>nd</sup>

recruiting care staff. During this time, Louis spent some days back in hospital. His unhappiness at returning to hospital continued to reinforce his trauma experiences. He continued to feel unsafe. This coloured his whole life, prompting stress responses, that were quite justifiable, but hard for unskilled carers to respond to appropriately. Louis was living with constant apprehension, fear, lack of trust

• HARMFUL IMPACT ON LOUIS OF STAFF CHANGES •

OF

LOUIS

IMPACT

ON

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IMPACT

As the year went on, staff left, for various personal reasons. Louis experienced multiple experiences of bereavement as cherished carers went. The trauma of loss triggering continuing trauma memories from hospital

• HARMFUL IMPACT ON LOUIS OF STAFF NOT UNDERSTANDING WHAT IS REQUIRED OF THEM •

ON

IMPACT

ON

LOUIS

OF

IMPACT

ON

LOUIS

OF

IMPACT

ON

LOUIS

OF

Trauma for Louis of ongoing trauma from being returned to hospital and being cared for by people who were committed but did not know how to support him

• HARMFUL IMPACT ON STAFF OF NOT UNDERSTANDING WHAT IS REQUIRED OF THEM •

IMPACT

ON

STAFF

OF

IMPACT

ON

Trauma for staff of encountering Louis's stress responses and not knowing what to do, how to make things better for him or themselves

• DIFFICULTIES WITH BENEFITS •  
 WITH DIFFICULTIES WITH BENEFITS •

Louis was not eligible for some benefits while in hospital, including the Mobility component of Personal Independence Payments.

Louis and his team needed transport for himself and staff to get between hospital in Dundee and Appletree - 70 mile round trip - and to get about within community, but Louis was not eligible for Motability, where Mobility component is commuted towards purchase of a vehicle. Louis was not able to initiate the Motability scheme for transport.

## Driftwood / Moving Forward

### Resources of support

#### Foundations: care-funding, housing and care arrangements

Louis's independent resources for Housing gave him a physical reality for his home

Funding for Louis's care at Appletree was agreed by local authority

The care organisation, whose senior management, including Chief Officer and the Head of Operations, were wholly supportive of the Appletree vision, Kate and Louis.

Kate had faith in the care organisation, through their track record of supporting people with complex needs and autism to be able to support Louis and his team.

After a year, care organisation raised pay rate for carers and agreed a Rural Premium also

## Visibility and political pressure

Scottish Government was working to deliver positive outcomes from Dr Anne MacDonald's 'Coming Home Report'. A clear commitment from the Scottish Government to address quality care for people with learning disabilities, particularly those detained in hospital, was a support to Appletree.

Kate was - and continues to be - part of this work. Louis's story was part of it, and Appletree as one solution for one man gave Appletree some national significance and profile.

Louis's story as a man detained in hospital was picked up by ITV Scotland News, featured in a news item. BBC Scotland Disclosures made a powerful documentary, nominated for an Amnesty International Human Rights Award, 'Locked in the Hospital' in which Louis's story was told, with Appletree filmed as a solution to detention in hospital.

Local MP and MSP visited and supported Kate with moral support.

Local newspapers covered the story, opening up a channel of community awareness of the project that gave Kate support, and over time, enabled her to find practical sources of help.

## Support to Kate

PAMIS is a nationally-funded charity that supports people with PMLD and their families.

The Family Support worker supported Kate to get her vision considered by the Local Authority.

She and the Chief Officer joined Kate's initial Working Group.

They also supported Kate through emotionally-draining challenges and setbacks, and were a sounding board, nurturing Kate's resilience and hope.

PAMIS gave some counselling time for Kate to support her through hard times.

Kate trained and practised as a Lay Reader up to and after the time of Louis being sent to England, then detained in hospital in Dundee. Her church community supported her with prayer. Bishop Ian Paton, her diocesan Bishop recognised Kate's work at Appletree as ministry, licensed her to Appletree. Colleagues invited her to share the Appletree story as a celebration of Love and the pursuit of justice, the celebration of community-building for a tiny group of marginalised people. This was an affirmation for Kate that what she knew was meaningful for Louis, intrinsically valuable, might come to have wider effect for others like him and herself.

Kate had friends with relevant professional experience who gave their time generously to talk over vision, implementation and sustainability matters.



## Training resources

Once Louis began to receive care, collaboration with Scottish Autism, PAMIS and Kate helped Louis's care team and therefore Louis and Kate.

Later, Cat and Maureen from PAMIS gave training and support to staff. Occupational therapy students on placement with PAMIS were a resource to demonstrate to staff—team purposeful and meaningful activity

Kate and Louis's knowledge and willingness to share and educate were a resource.

## Formation of *formal charity* (Scottish charitable incorporated) for people with PMLD/autism

Kate formed a registered Scottish Charity whose purpose is to benefit people with PMLD and Autism, their families and carers. This was a potential means of creating peer support for people with PMLD and their families. It was potentially a means of receiving charitable funding and driving peer-support by families, for people with PMLD, their families and carers

Founded in January 2021, as a Scottish Charitable Incorporated Organisation (SCIO), registered number SC050669, The Aiteal Trust has set itself to build relationships within the community of people with PMLD and their families. To date it has hosted four parties, bringing people with PMLD and their families together, to get to know each other, to have fun, to start building a community from the grass-roots upwards, where ideas and knowledge and hope can be shared.

It has contributed funding towards this Case Study, with a view to extending the findings to benefit others in similar situations.

The Aiteal Trust has benefitted from donations from generous benefactors. It works with other organisations and charities whose purposes align.

## Physical assets of Appletree

The space and buildings of Appletree had capacity to embody a vision of loving inclusion, through surrounding Louis and his team, his family and friends with space and beauty, to be a place of sanctuary, to lift spirits, to give everybody moments of thankfulness. It is a spec for long-term Belonging, for Louis, his family, staff members, friends and community.

A local estate donated the large rocks situated in the centre of the courtyard. A childhood friend of Louis's is commemorated through the central stone, his mother gave plants for the garden.

The Architect for the Appletree project, Colin Smith, had a vision for beauty as well as function, eg the tongue-and-groove MDF board that lines all the main rooms

Louis was involved in choosing colours for paint colours for the house, beautiful calm colours

John Mailer, the contractor and builder, engaged in a personal way, as did his staff, with Louis over the project. They continue to provide repairs and works, giving Louis continuity with those looking after his home.

The arrangement of buildings around a central courtyard gives physical security for Louis. The through-flow of house to garden is designed to offer Louis freedom and choice.

It was a practical resource, too, with varied spaces within the buildings and different areas of gardens, within which to create a meaningful and rich timetable of activities. There are raised beds, swings, a grass back- garden with a trampoline, space to run, play ball, space to develop in time small-time horticultural space eg polytunnel

Physical potential at Appletree for developing peer group around Louis. The barn, alongside the house offers additional potential to develop in time.

## Asset of time for community-building

Scope for time set aside to tell stories, develop communication with Louis, exploring Kate's vision - Kate and staff team together - to build relationships

Potential support for care team from managers and specialists within care organisation and from Allied Health professionals, to train and support staff to feel confident in interacting with Louis, to know how to support him, to recognise how to make him feel safe, to learn the art of self-reflection so as to recognise how the environment/context had pushed him into a Trauma response.

In all that, to create a well-supported, happy staff team wanting to commit

Potential time for building in truly Louis centred community

## Tools *for* communication

Louis story “all about me” was provided by Kate to help staff see Louis growing up, understand him

When staff began supporting Louis, Kate and Louis told stories about Louis and his life to help staff get to know him.

A digital passport was created for Louis and installed on his iPads by PAMIS, with training for staff to use it.

Kate encouraged staff to recognise Louis's speech. She shared documents about Louis's language, lists of words and phrases, nursery rhymes he used to convey meaning, a means to sing together, create pleasurable interactions. She encouraged staff members to listen to Louis's sounds, to distinguish words he used.

Communication suggestions from speech and language therapy

## Provision of *transport*

NHS Tayside lent Louis and his team an NHS vehicle during Louis's transition. They continued the loan after Louis left hospital and still do, while Louis (still) awaits delivery of a Motability vehicle.

## *Assets of relationships developed between Kate, Louis and the staff team*

*The relationships that built up between Louis, his care team, Kate, friends who came to support:*

*Carers loving Louis*

*Carers loving Kate, thanking her through birthday gifts, loyalty to her*

*Kate loving carers, thanking them, acknowledging what they do, willing to roll up*

*her own sleeves alongside them, bringing cakes, chocolates, publishing a book 'the*

*first year of Appletree', Appletree tee-shirts as thank you gifts*

*Enthusiasm in Louis, Kate and staff*

*Vocation*

*Kindness and energy*

*History of good times*

*Positive staff members*

*Staff positive excellence*

*Trusting relationship built up in 2023 between Kate and Practice Advisor, Kate and Operations Manager*



**Time during transition to become familiar with Appletree and daily routines**

Louis and his staff team embedded routines of daily living into their experience in transition.

Louis and his staff team became familiar with the building.

**Development of housekeeping skills in staff team**

Over time, staff team developed skills in housekeeping and in cooking.

There has been a marked development in cooking skills, with staff members taking a lot of pride and pleasure in providing nourishing and attractive meals for Louis over the year from Discharge to the present.

Development of *caring skills* in staff team and *capacity to communicate with Louis*

*Capacity to release community energy*

Kate, through thirty years of living in Strathearn and her former role in the church, had a network of connections that released positive energy from people wanting to support Louis and herself.

Generosity of neighbours and friends gifting time for activities for Louis and his care team at Appletree eg doing sessions of Felting, Bookbugs, horse-riding, attending parties and sharing their own assets e.g. inviting Louis to swim in their pool

John Mailer, Appletree's Building Contractor raised the profile of Appletree locally by proposing the Aiteal Trust as a beneficiary of an Auchterarder Round Table Fundraising Golf Event, in summer 2022

Appletree benefits from other resources of wider community eg Comrie Men's shed - have repaired Louis's rocking chair

Financial security during  
time when ineligible for benefits

Louis's Court-held funds subsidised his living and housing costs throughout the period of Transition.

## Water / What is the energy to move this forward

Water, life flow and overall occupations

Public pressure arising from the Coming Home Report and also the BBC Scotland Disclosures documentary  
the need to find and stick with a solution of care for Louis, despite setbacks.  
"Locked in the Hospital" which both featured Louis's case, that raised profile of Appletree and

Being thankful

Hope

Sense of vocation and commitment, even love, in staff and in Kate

Supportive multidisciplinary team holding the staff team

Louis loving carers

Quality care provided by some personnel.

Contribution at the start from former carer from Louis's life, to get to know Louis.  
who acted as mentor to staff team,  
assisting them to build up Care Plan,

Louis's affectionate memories for previous carer,  
Rob and the hope he has of meeting up again one day

Have to keep going for Louis's sake,  
a Plan B is unconscionable.







• ORGANISATIONAL • ORGANISATIONAL •

ORGANISATIONAL  
ORGANISATIONAL  
ORGANISATIONAL

Kate's feeling of powerlessness at times to improve the care arrangements. Kate and Louis are dependent upon services provided by the market model which are supposed to create choice, but do not.

Historic lack of a dedicated manager for Appletree who was also a 'fit' with Louis, and with the ethos, values, attitudes, beliefs in the vision for Appletree was a barrier to staff development.

Staff expressed their frustration at not being able to fulfil their potential autonomy, and at the loss of the original vision of team members each taking responsibility for different aspects of household care or activities.

Turnover of staff was not fulfilling vision of having a place with settled, committed care team

This turnover challenges the ways in which staff were needing to be supported to feel safe, and leaves them feeling unsupported.

Staff members needing 1:1 time to chat to discuss their worries fears and to receive positive input encouragement from those supporting them

Staff needing get togethers so that they can develop sense of being a community family

In the absence of support for staff, staff's anxieties expressed as coping behaviours that were frightening for Louis, and have potential to trigger trauma responses

Rather than creating a new culture of respect, centred on supporting Louis in his own home, enabling Louis to do as much for himself as possible, institutional behaviours continued in Louis's home setting.

Louis needs to be supported to feel safe and needs to experience a Stress-free environment. Without that support, he is stressed and expresses this. Louis's anxieties are expressed as behaviour that is frightening for himself, and for inexperienced and experienced staff. This sets up cycles of unhappiness between Louis and his care team.

• DANGER THAT LOUIS'S VOICE IS NOT HEARD • DANGER THAT LOUIS'S VOICE IS NOT HEARD • DANGER

When Louis's stress behaviours are not interpreted as reasonable communication of his needs, potentially he is seen as 'the problem.'

There is a need for a whole-system support for the team and Louis,

e.g. building mutual understanding in staff team,

coaching and supporting staff,

building relationships,

trust,

developing Louis's timetable.

• LOUIS'S EMOTIONAL AND PSYCHOLOGICAL STRESS MANIFESTED AS PHYSICAL ILLNESS • LOUIS'S EMOTIONAL AND PSYCHOLOGICAL STRESS MANIFESTED AS PHYSICAL ILLNESS • LOUIS'S EMOTIONAL AND PSYCHOLOGICAL STRESS MANIFESTED AS PHYSICAL ILLNESS

In November 2022, six months after Louis left hospital, a period of high stress for Louis and the staff team, Louis developed a high temperature and was sent to hospital by his GP for observations and IV antibiotics.

• LOUIS'S DEPENDENCE ON HIS MUM • LOUIS'S DEPENDENCE ON HIS MUM • LOUIS'S DEPENDENCE ON HIS MUM • LOUIS'S DEPENDENCE ON HIS MUM • LOUIS'S DEPENDENCE ON HIS MUM

This would be a risk for Louis long-term unless Kate mindfully prepared, as she does, to step back and to build capacity in staff team, in community friends, for the long-term

PERSONAL EMOTIONAL LOSS •  
PERSONAL EMOTIONAL LOSS •

Louis suffered the bereavement of his beloved,  
familiar Granny at the end of August 22,  
which affected him long-term.

Following this,  
Louis immediately voiced his fear that one day his mum was going to die.

## Driftwood / Moving Forward

Louis language has developed since leaving hospital, with committed care team

As staff members began to hear and understand Louis's words, to share them within the team, using mobile phones to send recordings to Kate for translation, Louis found his words were understood. Finding he got feedback, Louis was more emotionally satisfied and his language developed.

Louis went from one or two word utterances to complicated linked phrases of up to a dozen words, including sounds standing in for grammatical parts eg Phase 1 might be 'shop' Phase 2 'we're going shopping' now, Phase 3, 'We're going to go, we're going to go, we're going to go to the shops' and 'Give the lady the money'



The effect of Louis's language development has motivated staff

The development of Louis's language was noticed and celebrated by Louis's care team.

Deciphering Louis's language became a team effort,

between Louis,

staff and Kate.

It has helped build community

Kate understands much of what Louis says, words, phrases, quotes from nursery rhymes. This gives Louis confidence to use language to communicate with Kate to convey information.

Kate recognises phrases Louis uses, recognising he repeats what has been said to him and the tone in which they have been spoken.

**The effect of Louis's language development has empowered Kate as advocate**

Louis does not invent, Louis has no malice.

This enables Kate to get first hand reports from Louis of what has been said to Louis, by way of explanation of some of his stress behaviours.

Kate has been able to share these utterances within the care organisation, and wider, requesting that Louis's voice and his 'voice' are heard, in order to raise concerns about Louis's well-being.

Louis's increasing language, coupled with an increasing sense of security stability in his home and objects in it, is benefiting Louis's power of thinking

Louis's development of thought and expression is an opportunity for continuing lifelong educational development, artistic expression and personal satisfaction.

This is an opportunity to recognise and respond to.

Louis has internalised his weekly timetable of visits from Kate so he knows 'goodbye is not forever'. He trusts she will come back. He has internalised the routines of Kate saying goodbye. He may protest in anticipation, but is accustomed to her leaving and him staying.

Louis is able better to express  
his own wishes

Since leaving hospital,

increasing sense of security,

predictability of routines,

enables Louis to express his own wishes.

increased capacity for speech,

These wishes are respected and increases his sense of autonomy.

Louis's hospital stay in November 2022 was a demonstration of Louis's strengths and that he thrived with good care

Kate accompanied Louis for three days in a side-room in a General Adult ward, where Louis was treated with respect by doctors, nurses and care assistants. Louis tolerated IV drip, x-ray, ultrasound, huge range of new experiences. He enjoyed the social aspect of it. Carers came and spent a few hours to give Kate respect and Louis tolerated that too.

Louis's resilience, his capacity to move on positively, looking forwards rather than back - embodying forgiveness - is a notable quality

This period when Louis was settled in hospital, with quality care and understanding from Kate that made him feel safe, was in marked contrast with how unsettled Louis had been in Appletree in preceding months. This indicated for Kate that the difference could be attributed to how Louis was experiencing care in the two settings. It reinforced her belief that Louis's stress responses in Appletree were his voice, his communication and that he was not happy with how he was being cared for. It prompted Kate to act on what was happening at Appletree, with evidence from Louis himself. Shortly afterwards when Louis returned home, he gave further evidence to Kate that he was not safe with the care he was receiving.

Kate was afraid that Louis was being subject to abuse (intentional or not). She raised her fears with managers in the care organisation, with Social Services and with the Care Inspectorate.

Kate's concerns were heard and responded to immediately, because of Louis's vulnerability.

An Adult Protection Investigation was launched.

Once Louis and Kate's voices were heard as raising reasonable concerns,  
senior management in care organisation responded  
positively and practically to the challenges over leadership / management

Senior managers in the Care organisation re-committed to support for Louis and Appletree. They committed the organisation to practising values of a low-stress care environment, building staff confidence and capacity, to meet Louis's needs. They recognised the lack of an Appletree manager was an issue.

They brought in an in-house Practice Advisor who has been seconded to Appletree full time for three months, a year into the Appletree project.

The role of the Practice Advisor is to support the staff team and Louis by identifying stress responses in Louis and coaching staff on how to make Louis feel safe, how to create a low-stress environment in the house.

The Practice Advisor is encouraging reflective practice by the staff, practising and encouraging reflection into how they are interacting with Louis, what works, what might be done differently.

She and Kate periodically meet to reflect together, as both she and Kate practise reflective practice.

She is developing good practice for staff, increasing confidence in how to support Louis, their understanding of Louis, developing timetables of structured activities, working with Allied Health Professionals on Occupational Therapy recommendations for establishing and maintaining regular routines of activities, on Speech and Language Therapy recommendations for ways of supporting Louis to make sense of time, to plan, to learn to wait, to feel safe that good things are going to happen, familiarity with who is working with Louis, who is visiting and when.

The Practice Advisor is reviewing housekeeping arrangements, building team approaches to these.

She is overseeing management arrangements, making recommendations to senior managers, working with Kate and Louis to ensure their voices are heard and acted upon.



Care organisation is investing in staff

Suggestion has been made that the new Team Leader to be recruited should come with a practice background eg occupational therapist

Care team pay rates have been raised, a Rural Location bonus has been applied.

Recruitment agencies are being used to find staff, to create and sustain a critical number of staff who embody the values at the heart of the Appletree vision and the care agency's own values.

Training for staff is being provided through Multi-disciplinary community health team

including Speech and language, clinical psychologist, and PAMIS; Kate and Louis continue to model good practice

## Staffing support arrangements

Staff having had some opportunities to socialise as a whole team, while Kate has cared for Louis

Staff having had training opportunities that are also opportunities to build relationships, while Kate has cared for Louis and other times when staff, Kate and Louis have been able to socialise together.

PAMIS has supported team with training events, that were also community-building days

Allied Health professionals, Speech and Language therapist, Occupational Therapist, are training the staff team

## Louis's peer support

Louis's need for a peer group, peer group support was part of the original vision, based on Kate's familiarity with the importance of peer group to Louis throughout his life.

While the initially-envisioned second resident at Appletree did not materialise, Louis has been able to start building peer support through opportunities to socialise on a time-to-time occasional basis, as a start. Meantime, he has spoken wistfully about individuals he lived alongside in hospital and in his former care home in Glasgow.

Louis has had visits informally from a long-standing friend, who for eight years met monthly group with his family and Louis's for a church service followed by supper. Louis has kept a correspondence going with friends all across Britain, being supported to write, post and receive letters.

The Aiteal Trust, as a charity has capacity to develop peer support through developing opportunities to bring Louis and peer group and families together.

In May 2023 Louis joined a weekly community music activity designed for people with additional support needs. Louis was evidently so pleased to have that peer group again.

Other activities with this group will be explored.

There is scope for the Aiteal Trust to develop lifelong learning and creative opportunities for peer group/community to come to the Barn at Appletree, to give Louis the relationships that are so important to him.

**Family peer support**

Other families' passion for a similar life for their family members  
creates the potential for a support network amongst families that can be  
supported by the Aiteal Trust and other organisations.

**Louis has revealed  
his own inner strengths**

*Not letting go and perseverance*

## Collaboration between care provider and Kate, with PAMIS and HSCP over Louis's care

6-weekly multi-disciplinary team meeting

Collaborative risk assessment that enables the taking of appropriate risks to enable change. Autism, as a phenomenon that is behavioural, requires the practitioner to engage in relationship and put themselves on the line with their diagnosis. A therapeutic relationship should be at the heart of risk assessment.

Existence of framework of regulatory bodies to whom Kate might have recourse for serious concerns about Louis's care  
eg Care Inspectorate, Social services

Training given by PAMIS - using digital passport,  
storytelling, planning activities

Just as Kate and the Practice Advisor do reflective practice, together and individually, so does Kate link with colleagues from PAMIS, who likewise do reflective practice, and with the Allied Health Practitioners.

## Water / What is the energy to move this forward

Water - life flow and overall occupations

The importance of the Appletree prayer group. For Louis it is an opportunity to link with others from the community who love him which means that he and Kate feel safe.

Values reset through the application of reflective practise to understand the self, either as family member or staff within the context of Appletree

Kate adopting a 'peacemaking' approach, recognising the importance of the qualities and commitment of staff members to Louis

Through listening to Louis he is understood to be truthful and rational

Potential for and hope of development of a Multi-sensory storytelling centre at apple tree

When staff are supported their skills develop and they feel valued.

When Louis is supported and staff are supported everyone has fun

Student placements offer a resource through PAMIS to benefit Appletree

Developing a practice research agenda

The vision of the Aiteal Trust developing a centre for lifelong education along the lines of Camphill and L'arche with a focus on storytelling.



## CRITICAL REFLECTIONS

Kate and Louis are feeling peaceful and thankful in being able to say that at this stage of his journey Louis is feeling safe and is therefore flourishing. He is feeling safe because he has beautiful housing adapted for his needs, with a committed care team, predictable and meaningful activities within a network of loving relationships including family, carers and community.

The vision is being realised. The community is generating its own energy, which benefits everyone and serves as an alternative to the factors that lock in failure for individuals, their families, their carers, care organisations and professionals involved with them:

- A lack of love both conceptually and practically leads to systemic disablism and marginalisation. Policies are written in ableist language to further marginalise people with disabilities and by default locking them into the system.
- Neo-liberal (for profit) marketplaces emphasise the economic value of people with PMLD in creating market opportunities for stakeholders. In this model the government offloads responsibility and risk to others.
- A lack of community provision and access to human and social capitals essential for human flourishing.
- Models of commissioning services and fragmentation of service delivery in response to 'complex needs.' that lead to poor experiences for those cared-for and their families
- The deskilling/demoralisation of the workforce to a minimum wage. The professional groupings (psychiatrists, psychologists, social workers etc) become technicians of risk management focusing on public protection from the 'dangerous other.'
- The inability by many of those charged with caring to 'hear' the voices of those cared for as coherent, rational, and reasonable in their care context.

- The power differential between those looked after and those who do the looking after including their managers, senior policy makers, those charged with supervision eg social services, Care Commission, Care Inspectorate
- A lack of the development of skills in those who come into care in a professional role and lack of understanding of a Human Rights-based approach.
- A lack of spiritual understanding of patients as people who are equals and have the right to access societal resources for their wellbeing and flourishing.
- Initially, at least, a lack of familiarity with the humanity, language, personalities and fundamental reasonableness of those cared for, together with fear at their unfamiliar language and behaviours. This together with a lack of patience and/or time/resources to get to know them, and time that is required to build up relationship and trust means there is a gulf of 'difference' separating the cared-for and themselves. This leaves everyone feeling vulnerable.
- Quick solutions are sought that do not seek to ascribe humanity to the 'cared for' but treat them as a problem to be solved or a commodity to be allocated.
- Quick solutions often cause additional harm such as trauma to the cared-for by employing short-term physical and pharmacological restraint rather than taking the time to build nurturing relationships.
- The human rights of people and their families are disregarded, as the lack of love cannot comprehend the equality of opportunity and access for people with PMLD to a good life.
- This endowment of each person with absolute, universal, inalienable and inviolable rights means that they are already whole: equality is the acknowledgement, embrace and positive response to the whole humanity of the other.

## MAREE TODD MSP MINISTER FOR SOCIAL CARE, MENTAL WELLBEING AND SPORT

Statement on the Scottish Government's learning disability and human rights policies, including the commitment to support adults with learning disabilities and complex care needs to live in their home communities

Our vision laid out in [Scotland's Keys to Life Learning Disability strategy](#) is that 'People with learning disabilities should be treated with dignity, respect and understanding. They should be able to play a full part in their communities and live independent lives free from bullying, fear and harassment'.

[Link to report](#)

It is essential that Scotland provides support and services in a way which ensures that human rights are respected and protected. Scotland is committed to meeting its Human Rights obligations for people with learning disabilities, which are outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRC). This commitment has been set out in the Scottish Government's National Performance Framework and proposed in legislation through the Human Rights Bill. We are clear that the core business of government is to give proper effect to these human rights, in ways that improve everyday lived experience for individuals across the whole of the Scottish society.

The work that followed to find a suitable home for Louis, led by Kate, has shown that we have a collective responsibility to make this happen and this can only be achieved if we work together across multiple agencies and include the wishes and needs of the individual at the heart of this process.

Louis and Kate's story shows what can be achieved, and also some of the challenges that continue to exist. Experiences like theirs have inspired the vision that by March 2024 we want and need to see real change with out-of-area residential placements and inappropriate hospital stays greatly reduced. Progress continues but we know it will require a high level of collaborative and partnership working, innovative thinking, and commitment to solutions for individuals despite the challenges. We hope that stories of success like Louis and Kate can be inspiring for others to see what is possible. Moving forward requires us to celebrate the successes that have been achieved and to build on that across the whole of Scotland.

## The ongoing story

Appletree community is a celebration of love, storytelling and hospitality with Louis at the heart of it. What this difficult journey demonstrates is that it is possible to make a place of safety for vulnerable people (with a recognition that we are all vulnerable) to live together in hope. We feel that the experiences and the lessons of Appletree are of benefit to wider society through bearing witness to the capacity for healing within rather than separate from society.

Reflecting now, a year since Louis moved out of hospital into Appletree, looking wider, at the national challenge of creating communities around people with learning disabilities so they can feel safe, fulfilled, hopeful, as an alternative to detention in hospital, the challenges we experienced may be relevant to others. It may be the people charged with action are not empowered to take it, (not enough hours to do the work, or not understanding what people want, or not having resources, not fully having understood the vision), or that they themselves need encouragement and support to go forward confidently.

Our experience of researching points outwards from our particular case to the wider world. Our hope is that Appletree as a home for Louis is also an example of how others may find solutions specific for themselves. Our hope is that Appletree can take a role in bringing people together into a community of people with disabilities, their families and supporters, professionals, researchers, policy-makers, politicians, journalists, so as to engage with these challenges, that in doing this Appletree can be an example of radical hospitality that invites everybody to change the world together.

## Faith

There is a need at the level of person-to-person interaction for 'faith' in the other person, based on love and trust.

If we love somebody, treat them 'as' human, have experience in being able to trust them, we give them a level of autonomy that they recognise and have a choice to respond to.

That potentially is a turning point to change attitudes that deny the "other's" humanity, through overcoming them with force and violence, putting them on the outside.

It is a leap of FAITH that says 'this person is a mix of good and bad experiences, intentions just like me' and believes that treating somebody with LOVE in its widest sense - as a person, as valid, as equal - and in so doing, evokes a human response that affirms the faith and starts to co-create a faith story together.

“ Only everybody knows the truth ”



Goethe





