No Time To Waste

New Routes Home

Lived and Loved edition

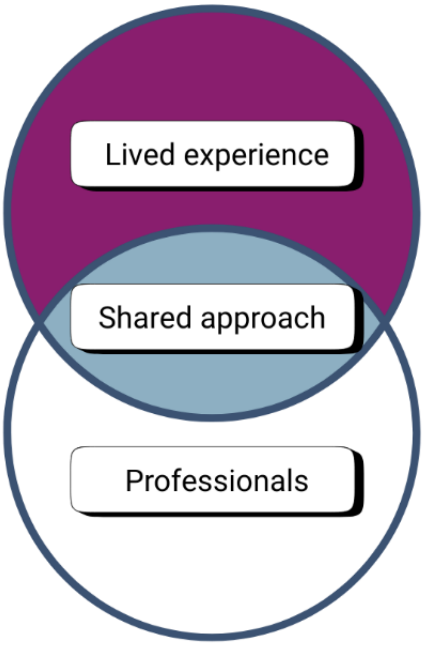
IMPACT
Improving Adult Care Together

A practical reflective toolkit focussing on approaches, power sharing, accountability and learning around long term hospital admissions and discharges for people with Learning Disabilities and Autistic People

Welcome

If you are here, you have taken a step towards working together to influence the system and get more positive results.

We have worked with a range of people with lived experience and professionals to coproduce two toolkits – one for professionals and one for individuals and families, these fit together to create a different way of working.



What is this and how do you use it?

This toolkit is for individuals, families and those closest to the person. It takes you through understanding how the system can get in the way for many people and walks you through an alternative approach that works.

If we are going to get the right answers we need to ask the right questions, understand what is important, and make the decisions that move us forward in the way that makes most sense to the person. To do this, those with lived and loved experience need to be at the heart of the process, with an equal seat at the table.

This is a framework to allow us to do that in a way that helps us –

- Start at the right place
- Work together in ways that make sense for everyone involved
- Equalise power and accountability
- Ask the right questions
- Have confidence to base action on analysis of what really matters and do more of the right things
- Move at the right pace
- Share our learning for next time

In the green boxes there will be questions for you to reflect on and record as you go through, at the start, and as you progress through using it. Answer them quickly and honestly and as you progress through the toolkit, you will get a better understanding of your situation, the approaches being taken, and any barriers to progress, allowing you to contribute to change effectively.

Contents

The first section is a practical toolkit exploring your experience of engaging with professional and organisational systems and responses and the impact of those approaches on the person and those around them.

The second section provides the reference material, case studies and related information. You can read this first if you want to, or you can refer to it at the end. The main point of the reference material is to provide additional support to you.

Background

The Coming Home Report [1]was published in 2018, highlighting the issue of inappropriate placements for people with learning disabilities and autistic people. Its Implementation Plan[2] aimed to make *'real change with out-of-area residential placements and inappropriate hospital stays greatly reduced'* by March 2024. Despite attempts to drive a change in pace and effectiveness of work with individuals in this situation, very little has changed for many people, since in many cases the same methods were being used, with some additional resources and scrutiny such as Dynamic Support Register meetings. These are important steps forward but need to be aligned with a different mindset and a substantial shift in accountability. The ability to create the shift in attitude and confidence to get substantially different results has been limited. Some areas sought to genuinely change the way they were approaching the situation, such as the Assertive Outreach Team in Renfrewshire, but these were not mainstreamed and are at risk of being removed despite their success. We need the whole system to shift to operate in this way with confidence or we always move at the pace of the slowest part of the system.

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[1] https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/

[2] https://www.gov.scot/publications/coming-home-implementation-report-working-group-complex-care-delayed-discharge/

Many people with Learning Disabilities and Autistic people who get stuck in long stay hospital admissions or out of area placements find it to be a long and torturous road back to the community. The stress and trauma created by the mismatch between what the person needs and what the system provides can result in massively increased risk for the person, their family and for those supporting them.

How do we measure what actions have been taken to avoid a hospital admission? How do we measure progress, when supporting someone to leave long stay hospital? Ultimately, what do we learn from the decisions that are taken, either at home or while in placements?

While people are stuck in hospital or inappropriate placements, there is often not focus enough on the person's quality of life, often taking away all the structure, all the connections, everything that gives the person's life meaning in the name of safety. With the right approach, this is avoidable, but even when we know this, it keeps happening.

Too many people still are expected to change to fit institutional systems and their expectations. Not enough attention paid to what is important to the person and where we got things wrong.

Family knowledge is not valued.

Opportunities to reflect and connect how the person is coping and learn from are usually missing.

Most responses list the limits of actions and services rather than what the person needs and wants.

The question being asked too often is "what will it take for the person to cooperate fully and be safe for discharge?"

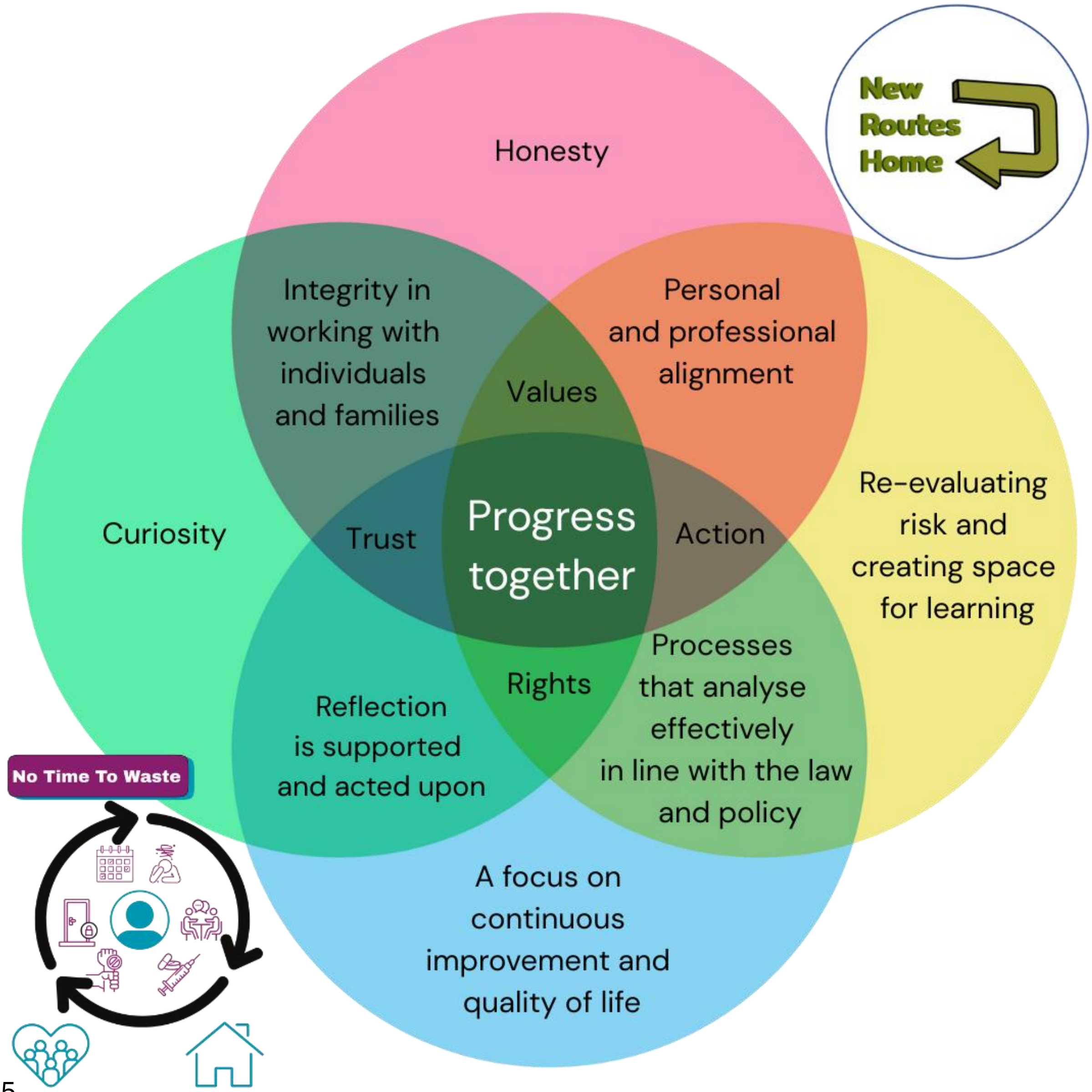
How do you feel about the points made in this diagram?

Which of these is present for you?

What are the strengths you can build on, what is getting in the way?

If you were to prioritise one place to start, what would it be?

The image below describes what we expect to see and experience when using the toolkits. If that is not happening, it should be reviewed with all involved.



New Routes Home

No Time To Waste

Which of these points do you recognise?

Can you write down what happened and how it affected yourself and your loved one?

Was there anyone that really helped? What did they do and why was it helpful?

Why?

There is a human and a financial cost of getting this wrong, we need to work together to reduce trauma for the person, family, and staff expected to carry out overly restrictive regimes. In addition, the waste of resources associated with delayed discharges and overly institutional settings in the community is crippling financially. Many individuals and families have told us that their experience follows a pattern. At the moment, too much decision-making power can sit with professionals, based heavily on their experience of the person in a crisis.

What has been the impact, positive and negative about the support the person has received over the years?

What made it valuable or not?

What did you learn from that situation that others need to know?

If families aren’t listened to, here are some common experiences -

Not listened to - left to cope when things started to break down

Actions feel slow, once things were of serious concern - people are often asked if you “want a bed” (hospital admission) feeling like there is no other option

Multiple traumas and negative actions can put you in a position where you feel you are pointing out things that don’t make sense

Ideas get dismissed too many times as unrealistic without being tried out

Months and years go by...

Trust and accountability can be hard to establish, if you push hard for change you can end up getting shut out

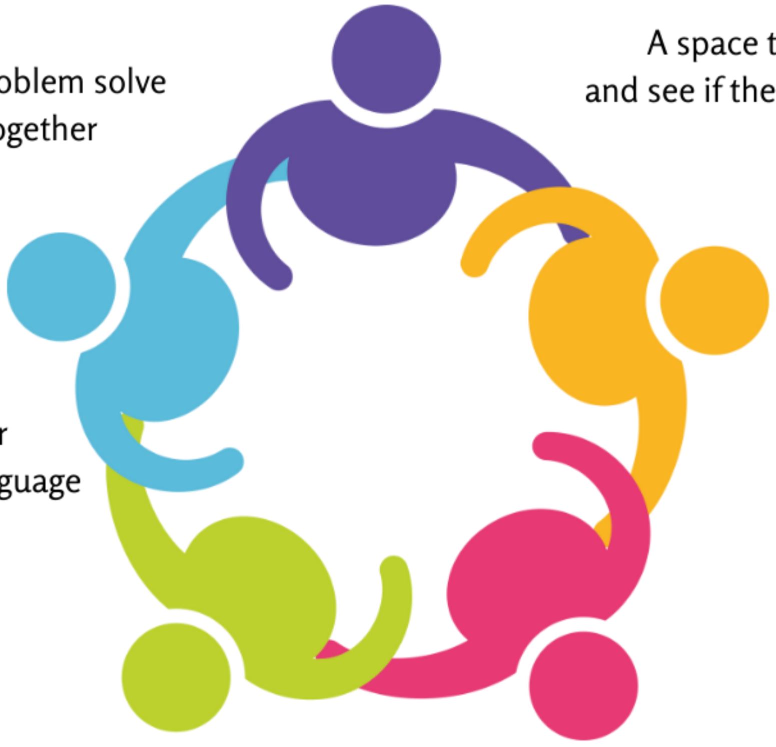
Have you experienced any of these things?

What was the effect on you, others, and the plans that were made about what to do next?

How?

We need to create a space where we are talking the same language and open to problem solve ideas together. A focus on exploration rather than process, problem solving rather than problem listing, Asking - “what would it take?” vs “what is wrong?”. This will allow us to balance who the person is, with what they need in a crisis. In line with Human Rights, the law and related policies.

The power shift we need relies on honesty, even if we don’t have all the answers. Below shows what should be part of this -



Honest open discussions

A space to try out ideas and see if they make a difference

Maximising rights and learning

Included and involved

Sharing experience of who the person is when they are not in crisis

Listened to

No jargon or judgemental language

Explore and problem solve options together

What does everyone understand about the person?

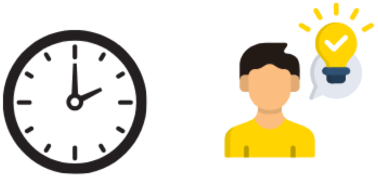
How can I give examples of this in a way that people will be able to relate to?

How do I structure my feedback in a way that helps them engage positively?

Otherwise, some professionals may base decisions on how the person is behaving under stress

Format the information in a way that makes sense to the professional

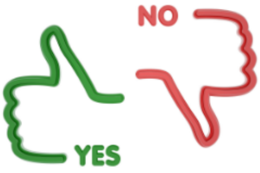
Give the information to the right person



Give the person the time to process information

Check they have got it and clarify any points they are unsure of

Check what they are going to do with the information

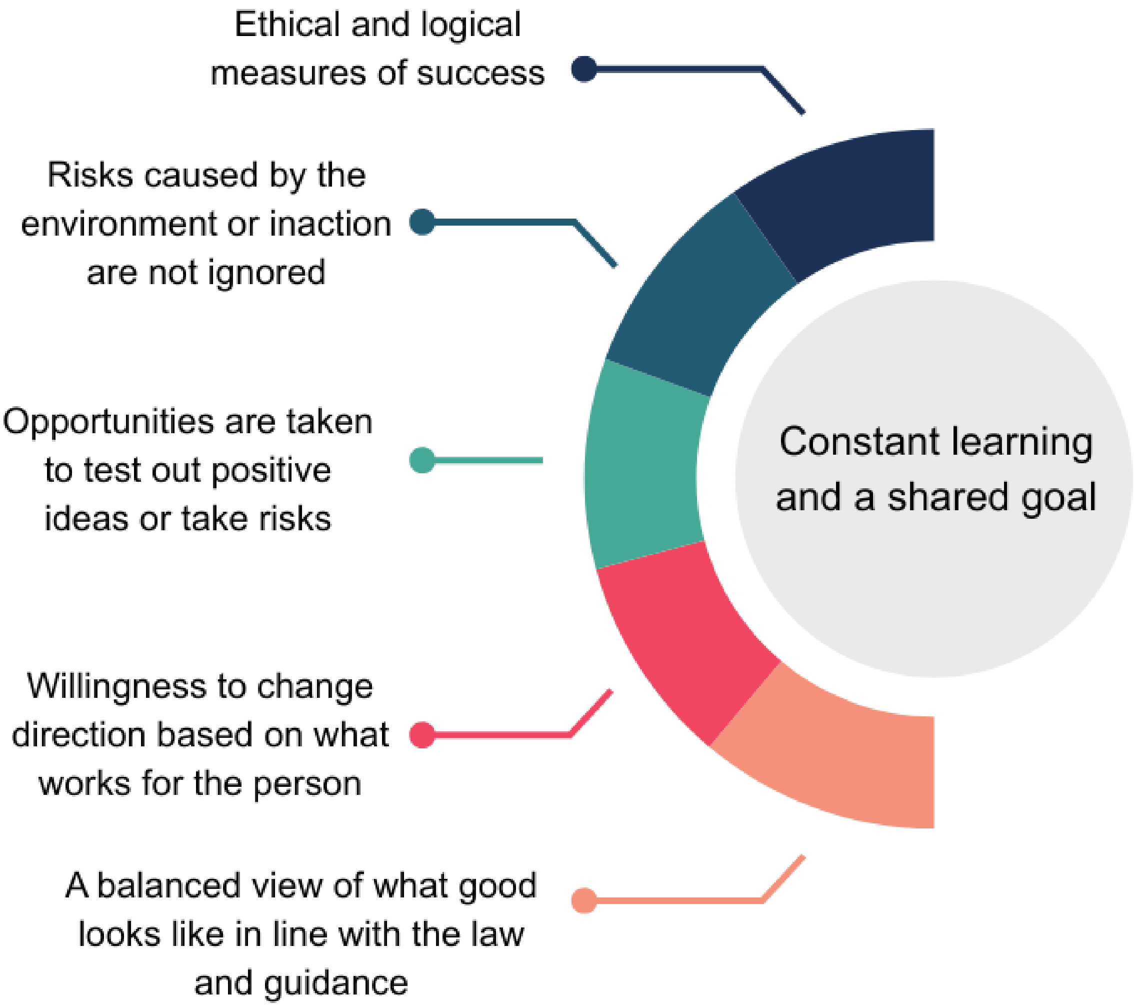


Let them know if that has helped or not, share any learning, consider if you need others to be involved

What are we focusing on?

Are services focusing on “presentation” and managing how the person behaves under stress? Or are they recording what has been found out about the difference between what’s important /what works for the person and what has been happening.

What is the gap in everyone’s understanding and approach between these different approaches?



What would help close the gap between our understanding and approach?

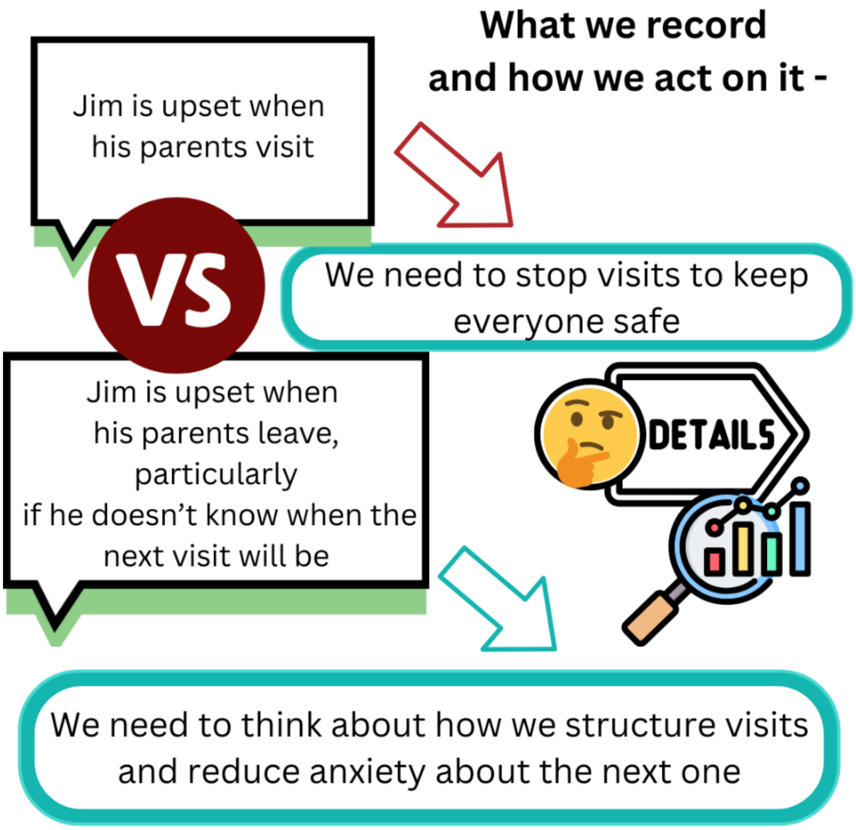
What would be an effective way to balance the risk and measure how ideas develop?

At this stage it is important to acknowledge that there will be professional boundaries, custom and practice and what feels safe to change.

Have you got access to advocacy support? Is it independent?

Are the questions they raise taken seriously and actioned?

Do you feel you are given time and space to contribute in a way that works for you - *‘I noticed this… I wondered if we should try that…can anybody suggest a way for us to…’*



What we record and how we act on it -

Jim is upset when his parents visit

We need to stop visits to keep everyone safe

Jim is upset when his parents leave, particularly if he doesn’t know when the next visit will be

We need to think about how we structure visits and reduce anxiety about the next one

Analysing information accurately and ensuring it is written down with all the context, does that happen?

Getting agreement and action – avoiding knowing what to do and going round in circles, are you experiencing this?

Are you supported to record what is likely and predictable as well as how the results we expect, and when we would consider changing direction?

Ask to agree this at the start to avoid shifting the goalposts later on.

If we ask the wrong questions it leads to the following cycle of flawed actions and analysis

The person is displaying unwanted behaviours

The emphasis is on reducing this behaviour through compliance in a place lacking many aspects of relationships, control and a homely environment

This is often attempted to be managed by reduced freedom (described as more of a controlled environment) and medication

The person either complies while still under stress or the restrictions continue to build

The person is either overwhelmed by the level of pressure to behave in the way that is expected or becomes becomes compliant through the use of medication, or the frustration and resistance continues to escalate further creating a false reputation

We should be asking the following

We strive to understand what works for the person (even if we can't provide it all) and we name everything that is causing potential harm

We act in a way that allows the person to trust us - Logical changes at a pace they can cope with

We alter what we do to fit what works for the person, not expecting the person to change to suit us, and explain this in a way that helps the person feel in control

We check that what we are doing is working for the person, and if not we continue to change it in a planned way until we get it right focussing on quality of life as well as discharge

We work on the transition to community as quickly as possible recognising that expecting the person to behave in a positive way whilst under high stress is unrealistic and not in the person's interests

Think about the way that decisions are made.

Is there thoughtful analysis of situations that take account of the whole person, are your points included?

Are there opportunities to create a space to explore ideas and feel safe?

Are steps taken to equalise power?

Does it feel inclusive and free from jargon?

PART TWO

Understanding the Different Approaches

There are two distinct ways that systems and individuals respond to people in crisis:

Approach 1

Reports look at what has happened and base plans around how everyone can be confident that the person is able to cope in a series of situations leading up to them being admitted, often in a service / staffing structure based mainly on how they present in hospital. Evaluation is based on professional assessments mainly, starting with the idea that training and professional opinion is the key to progress.

The person must achieve milestones to be confident to go forward and there is a focus on reducing risk through managing access to activities and situations. In this model the person is expected to show changes in behaviour in response to a set of situations within expectations and restrictions placed on them. The person's life gets smaller and often impacts heavily on meaningful structure and important relationships.

Approach 2

We ask 'who is the person?' not 'what is the behaviour are we seeing?' We start with the understanding that we need to change to fit in with what the person and those closest to them are telling us. We find out what matters to them and honestly record how much of that has been well supported, leading up to their admission to hospital. We then try to ensure as much of the focus is creating consistency and trust by delivering as much of what is important to the person to show that we understand that the purpose to our work is the person feeling safe, listened to, and well supported. We don't spend time explaining why we couldn't provide what the person needed, instead focusing on acknowledging it and appreciating what we can learn to ensure we don't repeat those mistakes. Using this Person-Centred model, we focus not on how the person needs to change while in a stressful environment, but how we can change what we do to be closest to what they need. We relentlessly focus on ways to minimise the anxiety, restrictions and avoid setting hoops for people to jump through.

In reality, most of what happens is a mix of the two.

When we feel powerless our response will be anger and frustration or hopelessness and depression. We need to recognise that there is a massive disparity in power, where professionals have the ability to pull out of plans and reset progress for a person at any stage. This results in everything happening at the pace of the slowest actions until we have every piece of the puzzle, with progress becoming fragile.

When risks feel significant, and power is not shared, it becomes easier to do nothing rather than professionals feeling a risk of blame if anything they change goes wrong.

This level of risk to professional accountability is not equitable to the pressure to acknowledge and be accountable for continuing to carry out actions which cause distress, reduce someone’s human rights and are preventable with another approach. A failure to recognise the impacts and do everything to counter those creates false barriers to progress.

There are a number of clear markers that determine both the likelihood of someone with a Learning Disability and / or an Autistic person being detained in long stay hospital or inappropriate out of area placement, and also the speed and effectiveness of planning for their return to the community.

One key focus will be on outcomes and learning; another will be exploring the power shift and accountability that should take place as a result of the questions we ask and our approach to the challenges we face.

We are emphasising a Human Rights and Trauma Informed approach which avoids blame, and asks us all to be really open and honest as work together on moving forward. By focusing on the right areas, we can avoid stalemates around what progress looks like and work together more effectively.

There are 3 key stages to consider –

- **Pre-admission / preventative work**
- **In hospital**
- **After discharge**

When to use it – when there is a concern that there a risk of hospitalisation or the person is already in hospital, whether everyone agrees they are planning a discharge at that stage or not.

Pre-admission

Identify common factors that were present before the crisis that led to admission, particularly what people understood about –

- The support the person was receiving
- The support the family was receiving
- The level of analysis of what we understood about how the person was coping and what was important to them
- Detailed analysis of all the factors influencing them
- Any change to support that was being asked for
- Any actions taken to change the level / focus / scope of support in direct response to information from the individual or the family
- Any changes to the person's life that impacted on their ability to cope
- Awareness of a deterioration in someone's situation, and the chance to plan to avoid admission
- Willingness to explore different options together

In hospital

- Recording what it would take to support the person well
- Honest recording of the barriers and the scope of what has been agreed
- Active involvement and support of those closest to the person
- How learning is captured and influences practice with the person and more widely

- The extent to which the impact of the conditions as and approach impact on the person, (positive and negative)
- The ability to change and innovate when an approach isn't working
- A focus on improving the person's quality of life while they remain in hospital
- Supporting the person to understand what the way forward looks like
- Analysing the effectiveness of decision-making protocols
- Minimising delays and being clear about the human as well as financial cost of any lack of meaningful action
- Being proactive around seeking possible solutions, even if this extends beyond currently available options
- Being thoughtful empathetic and consistent
- A clear focus on altering the responses and support from everyone around the person, rather than expecting the person to change their behaviour while under stress

After Discharge

- Coordination of housing, planning and support
- The type of support offered and its suitability
- The follow up to make sure things are working as planned
- Reviewing and proactive planning based on who the person is, not on solely managing behaviour
- How we are learning and adapting

Reflecting, Planning and Learning Together

We are all of equal value and the ability to explore ideas together without shutting down alternative approaches will create options that can be incredibly positive. This helps create a shared exploration of the issues and gives space for ideas.

Too often we have seen a rush for professionals to have “the answers” when they join the meeting, limiting the chance to take on new perspectives. Encourage the people supporting the person to use the template on the next page to guide your discussions.

Taking a position is exhausting and doesn’t help us feel safe to do anything different -This does not allow for trust and learning

Safe is a state of mind where the person can manage expectations, have access to people and routines / activities that are important to them in an environment that works for the person at that time

Safe is a space we can manage, where we can limit access to risk where staff can take control if they need to make someone safe

I have noticed this, I was wondering if you have seen the same thing?

It sounds like that isn’t working, what can I do differently to help?

It feels like he isn’t sure what is happening next, what things can we look at changing together?

So if we alter the social story, and try this for a month, we will check in and see if it is working for everyone

Making decisions together - using a reflective process
Give everyone the time to share and ask clarifying questions - explore the possible ways forward together
Don’t jump straight to actions

What is most important to the person - how do we know?

Use Person Centred Planning, gather feedback from people who know the person well

What do we feel we are getting right and why?

What are we concerned about and why?

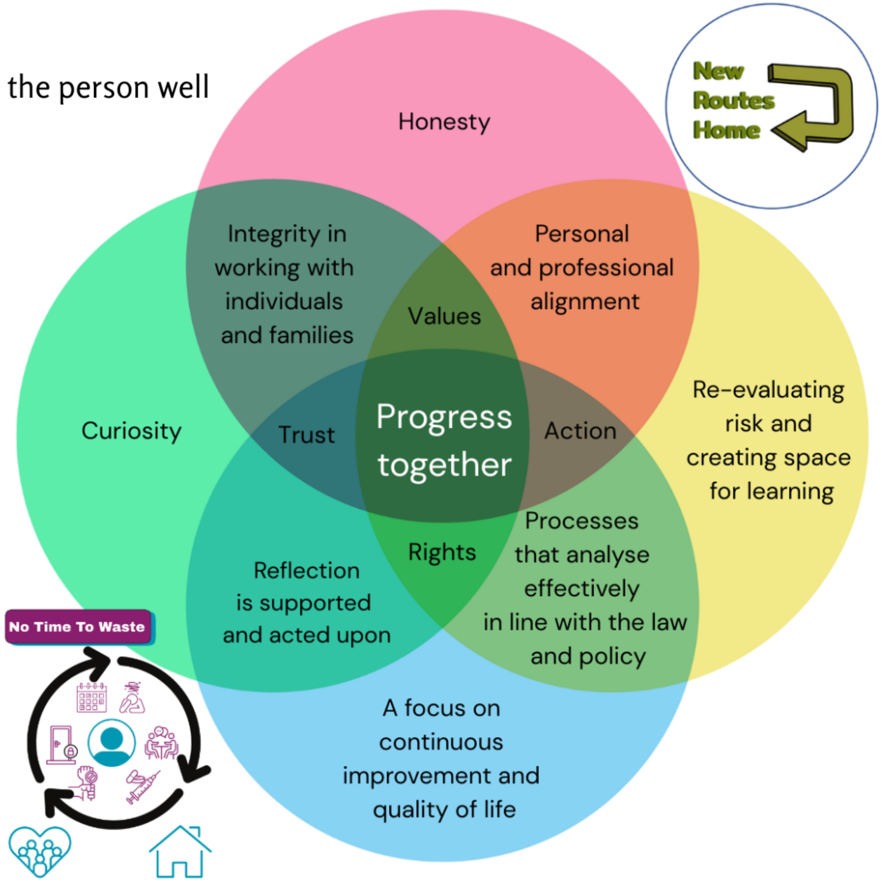
How are building on what is going well?

What evidence is there that the person is managing the current plan?

What are the opportunities and risks -

- If we make no changes
- If we make changes we think are better

Will the person see this as progress or something worrying?
Phrasing changes as positives - avoid the use of “no*



How can we make our actions predictable and based on the same principles , so the person doesn’t feel unsafe?

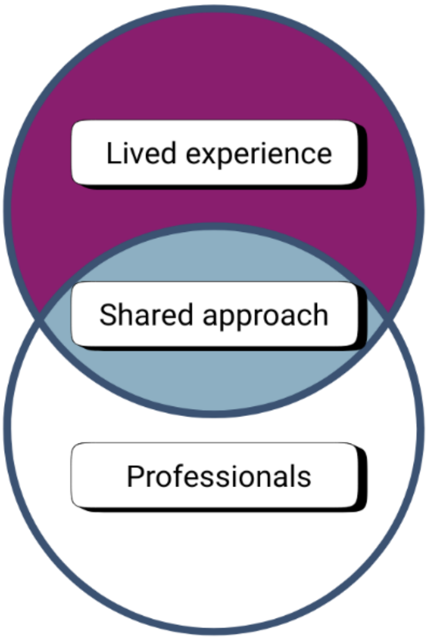
How do we build in clear steps that maximise choice and reduce the impact of any difficulties, giving a clear path back to positivity?

We check that what we are doing is working for the person, and if not we continue to change it in a planned way until we get it right

We work on the transition to community as quickly as possible recognising that expecting the person to behave in a positive way whilst under high stress is unrealistic and not in the person's interests

We hope this has been useful at supporting you and creating a real shared approach between everyone involved.

The next section gives some examples and resources, which should help you identify patterns that support the right approaches. We are constantly adding to the references section so please share learning with us at newrouteshome@gmail.com



Case studies / References / Resources

These are a range of quotes, documents and examples that should help reinforce confidence in the need for change, give more examples of how things were done and the learning.

Nobody that has shared these examples knows everything; we are all still learning.

Before we get into the more detailed examples related to hospitals, here is a blog post from the late Dave Hingsburger, former Director of Clinical and Educational Supports in Toronto, which illustrates a mindset that underpins where everything can start to go wrong. His books Behaviour Self, Just Say Know and Do? Be? Do? are amongst the most powerful and readable examples of human analysis of what the system is doing and reframing it in ways that make sense to everyone.

If we do not recognise the smaller losses of freedom, the compromises to what makes sense to the person, we risk building a string of smaller traumas that eventually becomes unbearable. Be aware if you are denying someone their rights or cutting corners, the human cost can be huge.

10:00 O'clock Pear

I had my 10 o'clock pear at 8 this morning. I live a lot of my life like that. The cool thing is, I get to make that call. I get to feel the regret for eating the pear now, when 10:00 hits. But right now the pleasure of the just ripe, just right, pear is still tickling at my taste buds. So, I'll cope at 10. I will. I've learned to, because I make tiny little decisions that have tiny little consequences all the time.

The other day I heard a mother say to a teen aged child with a disability, "No, you know you don't have snack until 2." It was 1:45, I shit you not. The girl, looked defiant for a couple of seconds and then sat back into compliance.

Really?

That mattered?

Really?

I know, I know, I know, that I don't know the people or the situation and there very well might have been a reason for the 15 minute delay. So don't. But can we all realize that people with disabilities are over programmed, over scheduled, over controlled and worst of all, over ruled, all the time. All. The. Time.

Simple requests get called behaviours.

Realistic disagreement gets called non-compliance.

There's a lot more names that we call people with disabilities, isn't there?

But when you live in a world where you:

Have to ask for a snack when others your age simply get what they want from the fridge.

Have to eat on a schedule you didn't set and probably weren't consulted on.

Have no flexibility on that schedule or any other schedule.

Isn't there a need for even the tiniest of rebellions?

"Speak up!" "Disagree!" "State Your Point!" I yelled all these things in my mind.

But she doesn't need my voice.

She needs her own.

I pray one day she'll have one.”

Dave Hingsburger Blog - Of Battered Aspect

Resources

Tick Tock - Scottish Human Rights Commission

“Tick Tock…”

Hospital Is Not Home - Mental Welfare Commission

Hospital is not home

Are We Heading In The Right Direction? Scottish IMPACT Network Long Stay Hospitalisation 2023 -2024 - New Routes Home

IMPACT Case Studies

Coming Home Implementation Report – Scottish Government

Coming Home Implementation: A report from the working group on complex care and delayed discharge

Assessing Risk in Institutional Settings - Easy Read Guide – New Routes Home

Assessing Risk in Institutional Settings

A New Way Home – Frances Brown and John Dalrymple

A New Way Home

Disclosure Scotland Locked In The Hospital – BBC 1 Scotland

https://youtu.be/84bjO-8lvH8

Risking a Real Life - In Control Scotland

Risking a Real Life

Counterfeit Deviance - Griffiths, Hingsburger

‘Counterfeit Deviance’ Revisited

Policy Map

INTERNATIONAL LAW

- Convention on the Rights of Persons with Disabilities
- Convention Against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment
- Convenant on Economic, Social, and Cultural Rights
- Convention on the Rights of the Child

U.K. LAW

- Human Rights Act 1998
- National Assistance Act 1948
- Equality Act 2010
- (Whistleblowing) Public Interest Disclosure Act 1998
- Criminal Justice and Courts Act 2015

SCOTTISH LAW

- Social Work Scotland Act 1968
- Adults with Incapacity (Scotland) Act 2000
- Carers Scotland Act 2016
- Mental Health (Care and Treatment) Act 2003
- Community Care and Health (Scotland) Act 2002
- Adult Support and Protection Act 2007
- Housing Scotland Act 2014
- Patient Rights Act 2011
- Criminal Justice (Scotland) Act 2016
- Public Bodies (Joint Working) Act 2014
- Social Care (Self-Directed Support) (Scotland) Act 2013

SCOTTISH POLICY

- Getting it Right for Every Child (GIRFEC)
- Getting it Right for Everyone (GIRFE)
- Towards Transformation
- Mental Health and Wellbeing Strategy
- Health and Social Care Standards
- Care Programme Approach

RESEARCH AND EVIDENCE

- Coming Home Report (Scottish Government)
- Coming Home Implementation Report (Scottish Government)
- Tick Tock (Scottish Human Rights Commission)
- Challenging Social Care Decisions (MECOPP)
- Hospital Not a Home (Mental Welfare Commission)
- Housing for Complex Needs (Heriot Watt University)
- Too Complicated to Treat (AMASE)
- Accountability and the Implementation of Self-Directed Support (In Control Scotland)
- Not Included, Not Engaged, Not Involved (Children in Scotland, National Autistic Society, Scottish Autism

Jargon buster

You can only take part in a conversation effectively if everyone understands what is being said:

- CAMHS - Child and Adolescent Mental Health Service.
- Counterfeit Deviance – Where someone with a Learning Disability or Autistic person has acted inappropriately through lack of understanding or poor guidance, but have been labelled as having deviant sexual tendencies.
- CPA – Care Programme Approach, a format for planning with people who are in hospital.
- CTO – Compulsory Treatment Order, a legal order that allows someone to be treated in hospital or in the community.
- Guardianship – a court ordered appointment of someone to make decisions on behalf of an adult who lacks the mental capacity to make those decisions themselves. Can be for welfare or financial matters.
- HSCP – Health and Social Care Partnership.
- Mens Rea – the ability to understand the consequences of your actions, important when defining the intent of someone’s behaviour.
- MHO – Mental Health Officer.
- PECS -Picture Exchange Communication System, a visual communication tool.
- Presentation – how a person is behaving, what is visible. Not an indication of how the person is coping or how they are feeling.
- PRN – as required medication which should be given in an agreed set of circumstances.
- SALT – Speech and Language Therapy, can be involved in eating and swallowing as well as communication.
- Talking Mats – physical visual communication tool.

Case studies

Case Study 1

I went to work with someone who had been described as having better verbal skills than his cognitive abilities. He was keen to impress people and would try and engage in conversations with other people and not say if he didn’t understand what they were talking about. He would then feel embarrassed that people could see he wasn’t following the conversation and that put more pressure on himself.

He had been returned to hospital three times in a fairly short space of time, and these had often been related to issues with relationships and alcohol.

The first time I met him I could feel his anxiety, he wanted to say the right thing and get out of hospital, and so I said to him that I needed his help. He asked how he could help, and I said I wanted him to tell me if I wasn’t explaining things clearly. I gave him permission to stop me and tell me I needed to explain it better.

He visibly relaxed as he no longer had to pretend he was following the discussion if he wasn’t and that I was clear it was me who needed to do better, so there was no sense that he had failed. This also set up a neutral power dynamic where he could challenge me and ask questions which made a huge difference as he wouldn’t do that before.

His experience was that he would struggle with conflict and be unable to disengage from the anger and frustration, talking constantly about how unreasonable the other person was being until the Police got involved, he resisted, and he was physically restrained and then returned to hospital often soon after. This pattern had repeated, and he had never successfully managed to return to a calm relaxed state in these circumstances. It didn’t seem to matter if he had skilled support or minimal discussion, it never ended well.

We identified the key factors and suggested an alternative approach. When a situation like this happens the staff member could say “I am heading back to the flat now” and start walking back. We would not discuss the incident on the way back, it was important that he didn't feel he was being ignored but no matter how he tried to engage with us in discussion, we wouldn't do it.

We explained to him this was what we would try and that after 20 minutes of being back at home, we would come through and ask if he was ready to talk about it. That way we would be away from the situation and the person involved. We went over this with him – this was to help keep him safe and find a better way as what had happened before wasn't working. We were clear staff would walk in the direction of the flat but try to physically guide him, as that had been a problem in past support settings. We allowed him to check it out many times with us when things were calm, "we will do this, and this is why".

The first time we used the approach, he followed the staff member home, was quite agitated and did try to engage in discussion a couple of times on the way back, but his anxiety did not become unmanageable. After 20 minutes, we asked if he wanted to discuss it and he was still highly anxious and not in place to be able to discuss the situation. We learned later that he had spent the 20 minutes looking at the clock waiting for it to be time to discuss it.

We said sorry we got that bit wrong, we will keep the first part the same for how we respond, but when you come home, you let us know when you are ready to speak about it. That could be 20 minutes, it could be the next day. We also said if we didn't feel he was ready when we started discussing it, we would say so.

Through this process we were able to establish trust and successfully break a pattern of readmission through predictable, reliable support that that gave him what he needed.

When something works, it's important to stick with it consistently. If we become complacent and stop following it, we may only then realise it was effective, because it was meeting the person's needs and helping them navigate a difficult situation.

Case Study 2

A person with a history of trauma was coming out of hospital after spending several years in hospital. The Consultant’s idea of safety was to replicate much of the hospital environment and gradually reduce restrictions. Through the work we had done with the person we identified another way. The expectation was for bars or window restrictors on his flat windows, as he had regularly climbed out of windows and been chased by the Police. We said we were going to use neither as his door was not going to be locked, we prepared him for a different set of responses from staff.

He had been frustrated at the lack of a routine that worked for him in hospital so he pushed staff as hard as he could until someone gave in. We were starting with a routine he had designed, and he had planned meetings with management, so he wasn’t only listened to when there was a problem.

When he did try to run, he got to the corner and when he saw nobody was chasing him, he hesitated, the staff member had prepared for this instance and put out two cups of coffee on the picnic bench outside his flat.

An invitation and a clear way back with no loss of face. These are the ways we change years of negative patterns.

The same man also was told he had to have a member of staff in his one bedroom flat overnight to begin with. This was someone who struggled to disengage and had never ended a period of anxiety in the presence of others without physical restraint. There was a member of staff at the bottom of the stairs, connect by smart tech, but there was an insistence he would not be discharged if this was not in place.

I agreed to it for two weeks maximum as I thought it was high risk for both the individual and the staff member. The support was removed after two weeks, and he never needed that constant input in his flat overnight.

Often too much support can be dangerous as the person can’t escape the interaction. More is not always safer.

Case Study 3

Someone who didn’t feel safe enough to put down his belongings and used to self-injure regularly was planning to move to the community after years in hospital. As part of the move to a 4 person group home, we organised some stays at a respite house so everyone could get to know each other. He spotted a magazine rack full of magazines. In his ward they would have been destroyed, and he gathered them all on his lap, marvelling at them.

After a while I persuaded him to put some back and just keep a few. The second week he put down his belongings and was visibly relaxed. On returning to the hospital, I passed the information to the keyworker who listened but clearly was sceptical.

The following week we had another stay, this time I requested that the key workers from all four men came along, but stay in the background, and see if they saw what I did. The man was again relaxed, feeling safe he put down his belongings. The keyworker said he would not have believed that change was possible in five years let alone two weeks.

This man had no verbal communication, he felt it was safe and despite his current living conditions and previous experience, he quickly trusted the people around him. If we don’t get the chance to show how life can be different, we will only see someone in crisis.

Acknowledgements

This toolkit was written by **Alastair Minty** and **Pauline Lunn** from In Control Scotland, coproduced with members of New Routes Home, and was funded by IMPACT. Special thanks to the coproduction group who gave their time and expertise:

Sylvia McMahon, Ruth Hughes, Karen Malcolm,

Andrew Malcolm, William Rae, Bruce Stewart, Debbie Forsyth,

Tony Young, Merwain Graham

New Routes Home is a collaboration of people with paid and lived experience, who meet regularly to share practice and advocate for change.

Anyone with an interest in deinstitutionalisation is welcome to join.

If you would like to know about New Routes Home email newrouteshome@gmail.com visit our website https://newrouteshome.wixsite.com

IMPACT is the UK centre for implementing evidence in adult social care.

Working across the four nations and with co-production at its heart, they draw on insights from research, lived experience, and practice knowledge to make a difference to front-line services, and to people's lives.

In Control Scotland is a small Scottish charity that works collaboratively for a fairer system of social care support.

They are the host organisation for New Routes Home. You can find out more about In Control Scotland on our website: www.in-controlscotland.org