Submission to Scottish Government

"How people with complex needs can be helped to leave hospital"

Blackwood's Concept Home

Jane Gray, Chief Executive, Ark Housing Association
on behalf of;

The Good Life Group
October 2016

Summary

At March 2015, there were more than 600 people with complex needs who had been in hospital for more than a year ('Category B'). Some had been there for more than 10 years. For many of these, there is apparently no suitable community based living solution available.

We believe that there are community living solutions for many of those affected and that the Scottish Government's '20/20 Vision',

"…that by 2020 everyone is able to live longer, healthier lives at home, or in a homely setting"

should be achievable for most, if not all people with complex needs.

We believe that the commitment to hospital closure in 1996 should be maintained and that if it is not, we are in danger of developing a new population of people whose lives are lived in hospital.

The demographic, not just of older people, but of children and young people with complex and enduring needs, will exert increased pressure on resources and we need a national strategy to ensure that these children do not become the institutionalised population of the future.

The recent report by the Mental Welfare Commission ('No Through Road') highlighted the unacceptable delays being experienced by people with a learning disability. We want to help fix this for those with learning disabilities and for the wider group affected.

The Scottish Government Independent Review of NHS Continuing Health Care in 2014 and the subsequent letter of guidance on Hospital Based Complex Clinical Care issued in May 2015 placed a responsibility on all parties to address this issue.

We want to help fix this problem and believe that, in order to do so, the Scottish Government should consider;

- Identifying a Director to lead in tackling this
- Making planning for this group a formal requirement for all government departments and relevant agencies
- Developing a funded plan to allow those currently living – unnecessarily – in hospital to be discharged to a community setting by 2020
- Developing a funded plan to prevent future unnecessary admissions of people with complex needs

We will commit to using all of our resources and influence to ensure that the housing and care sectors bring forward innovative solutions that meet people's needs and aspirations. We want to work with government to demonstrate that this approach is affordable. But most of all we want to give people a fair chance to have the best possible life quality.

The Good Life Group

We have joined forces to maximise the chances of tackling this problem. We are;

ARK housing association
Bield housing association
Link housing association
Viewpoint
Blackwood
Trust housing association
Hanover housing association
Horizon housing association
Key housing association
CHAS
SFHA
Barony housing association
Kindred
ALACHO
CCPS

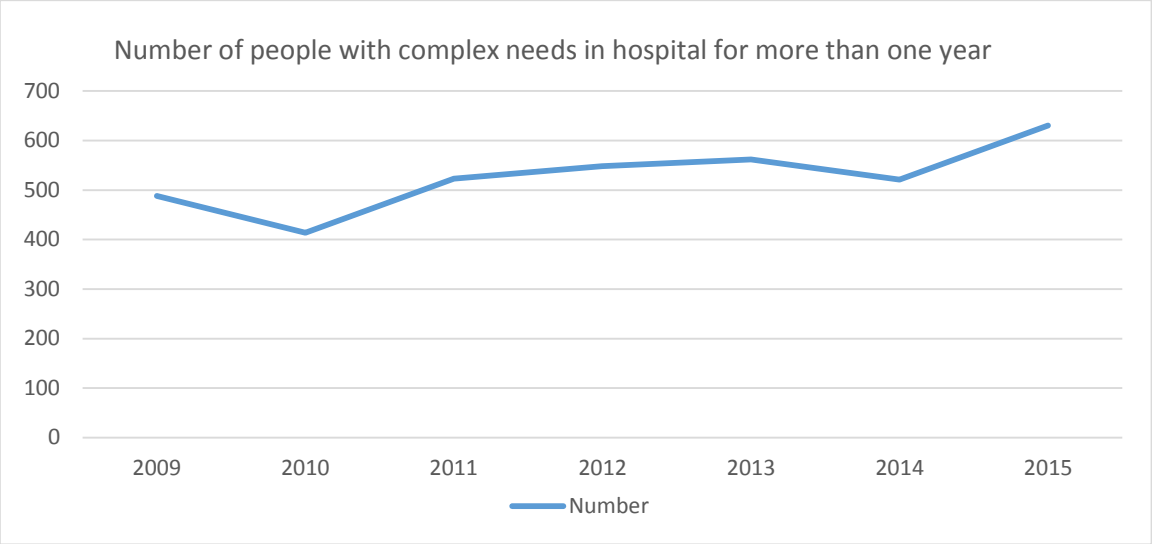
And we have the experience, knowledge and people who can help to fix this. But we need help from the Scottish Government.

Background

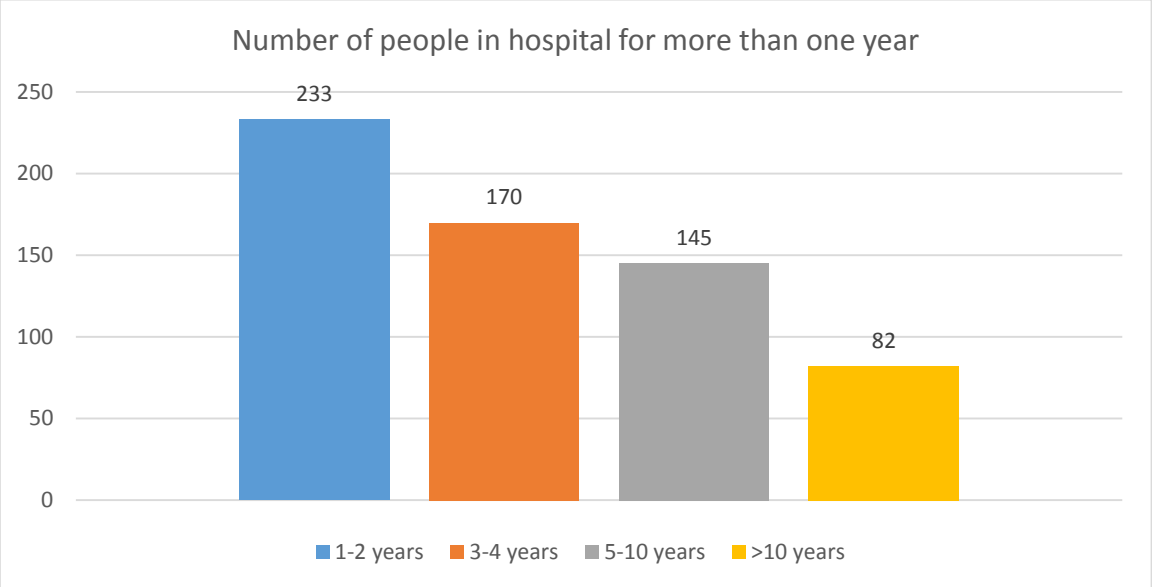
Scottish Government data[1] suggest that there is a high number of people in hospital in Scotland, not because they need to be in hospital, but because no community based living solution is available.

The main reason why no such solution is available is financial but there are also other challenges such as the availability of suitable accommodation and care.

This is not a recent development, but the scale of the problem is growing;



More than 80 people have been in hospital for more than 10 years.
Nearly 400 people have been in hospital for more than 3 years.



[1] 2015 Continuing Healthcare Census and 2016 Inpatient Census (HBCCC)

The above numbers are based on what were previously called, 'Category B' cases. These were people who no longer met the criteria for Continuing Health Care (CHC) but were nevertheless still in hospital. It is recognized that most people within this category will not have had a discharge date agreed. However, given the very long lengths of stay shown above, it is very difficult to justify their continued stay in hospital.

The 'Category B' definition is no longer in use. Instead, CHC has been replaced by Hospital Based Complex Clinical Care' (HBCCC) and, at the March 2016 Census, there were 1,630 patients receiving HBCCC (of which 1,128 were mental health and learning disability inpatients). It has to be assumed that these people require hospital based care.

However, anyone who is in hospital for more than 6 months, defaults to HBCCC and some of these will be former Category B patients. It is not yet possible to quantify that sub-group. Further, the delayed discharge definition of Code 100 includes people from both the old Category A patients (those who met the CHC criteria but who do not meet the HBCCC criteria) as well as some former Category B patients who can be cared for outside hospital but where services have yet to be commissioned.

In summary, it seems very likely that there are at least 630 people who are, in effect, living in hospital, when their needs could potentially be met in the community. This figure was accurate in March 2015 and, given that the trend was, at that time, an increasing one, it is highly unlikely that the figure has reduced. It is more likely to have increased (but the new recording system makes it difficult to prove this).

Our work so far….

We are working with health and social care partnerships in Aberdeen, Angus, Edinburgh and Falkirk to help reduce delayed discharge for those with a potential housing solution. At the same time, we are gathering information to help understand why people come to be stuck in hospital in this way in the first place. This work is not yet complete but we have identified some important issues already. For example,

- Some people are ready for discharge and a community living solution is available but the cost of the care package is deemed too expensive. Such cases are competing with other client groups whose care packages will be significantly less expensive. Given resource pressures, partnerships are seeking to deal with as many people as possible and this disadvantages high cost cases.

- Some people were admitted in a crisis (sometimes a housing management crisis, or because carers couldn't cope any longer, or had died). If swift action had been taken, people could have returned to community living. Sadly, what started as an emergency admission then turns into a long term arrangement – and during that time, the person's ability to live independently reduces as a result of institutionalisation.

- Whilst hospital teams have concluded that no suitable alternative exists, housing people have considered some case studies and believe a community solution is achievable.

- We are working with Kindred to understand the requirements of the emerging population of children and young people with complex and enduring conditions.

The housing and care sector already provides solutions for those with complex needs. Such community based solutions have developed over the past 30 years and can now meet the needs of those with complex needs who would previously have been forced to live in an institution as illustrated in the following case study;

Living a good life after 40 years of incarceration: the story of two people.

Organisation A was commissioned to provide housing, support and care at home services for two people who had had been resident in hospital for more than 40 years and who have very specific, high level care and support needs. Both are diagnosed as being on the autistic spectrum and display distressed behaviours.
The built environment, support and care have been specially designed to be supportive for people with this diagnosis.

The two individuals are now leading the life they could always have led.

This was a partnership project between the housing and support provider (a housing association), the local authority Social Work Department, the hospital, other NHS professionals, the individuals and their families.

Initially, the key challenges were to ensure the safety of both people and that of staff and the public.

To accommodate the requirement for a specialised built environment, two properties were purchased, which were re-designed and specialist adaptations installed. The accommodation required sound proofing, strengthened walls, toughened glass and all fixtures such as lighting and switches, to be flush to walls. The challenge in providing such specific accommodation is achieving a balance between safety and security for the service users and staff, and providing a warm, inviting and homely environment.

Person-centred tailored support services

The key aim of the person centred support was and continues to be to reduce distressed behaviour and increase quality of life: to maintain existing skills but, more importantly, to enable the development of new skills therefore increasing independence, and the promotion of choice, autonomy, self-esteem and confidence.

The combination of the person centred environment and support services has seen an improvement in the physical and mental health of both people.

- Sleep patterns have improved
- Diets have improved and levels of exercise increased
- New skills and abilities developed
- Regular contact with the local community facilities
- Levels of anxiety have decreased, evidenced by:
  - A reduction in noise levels
  - Reduction in the use of “as required” medication
  - Reduction in destructive and distressed behaviour
  - Reduction in the use of physical interventions

Costs

Each person receives 210 hours of care each week requiring funding of approximately £180,000 per year. Government data (ISD 2015 Costs Book) reports the weekly cost of an LD inpatient hospital bed is in the order of £3976 giving an annual cost of £207,000. This suggests that the community solution is costing 13% less than the hospital (and is expected to decrease further as dependency reduces).

What is needed to fix this?

We believe that the following are the main measures needed to fix this problem;

1 Treat this as a one-off problem

So long as people with complex needs have to compete with other, less expensive client groups (most notably, older people), they will never be first in line for care funding. Provided future admissions can be prevented (see below), there is a strong case for seeing this as a one-off issue – that is, there will be no additional costs once solutions have been found for existing cases.

Using an illustrative figure of 500 people who could be discharged into a community setting, the care costs of that group would be as follows, based on annual costs of £100,000, £200,000 and £300,000 respectively;

- 500 x £100,000 = £50m pa
- 500 x £200,000 = £100m pa
- 500 x £300,000 = £150m pa

Based on the above example (and the experience of organisations involved) the costs of community based care are probably similar or less than those of hospital based care. The following factors should also be noted;

- in order to fund the community based care costs, the hospital beds would ideally be closed (see below)
- future community care costs may reduce as independence grows, and
- demand for hospital beds will almost certainly increase if nothing changes

2 Preventing future admissions

We already know some of the reasons why this happens;

- Carers grow old and cannot cope any more
- Carers' circumstances change and they need help such as a bigger house
- There is an incident in the community and people suffer ill-treatment (eg harassment)
- People's own needs change as they grow older and different forms of care are required
- There is little future planning with the emerging population of young people and their families.

We are working to develop a better understanding of these issues but it is clear that many of these problems could be anticipated. We therefore want to work with councils, GP's and others to build in systems which will flag

up these predictable triggers and ensure that proper plans are in place to act quickly when, or before, they happen.

An application has been submitted to Healthcare Improvement Scotland under their Improvement Fund in order to progress the above work.

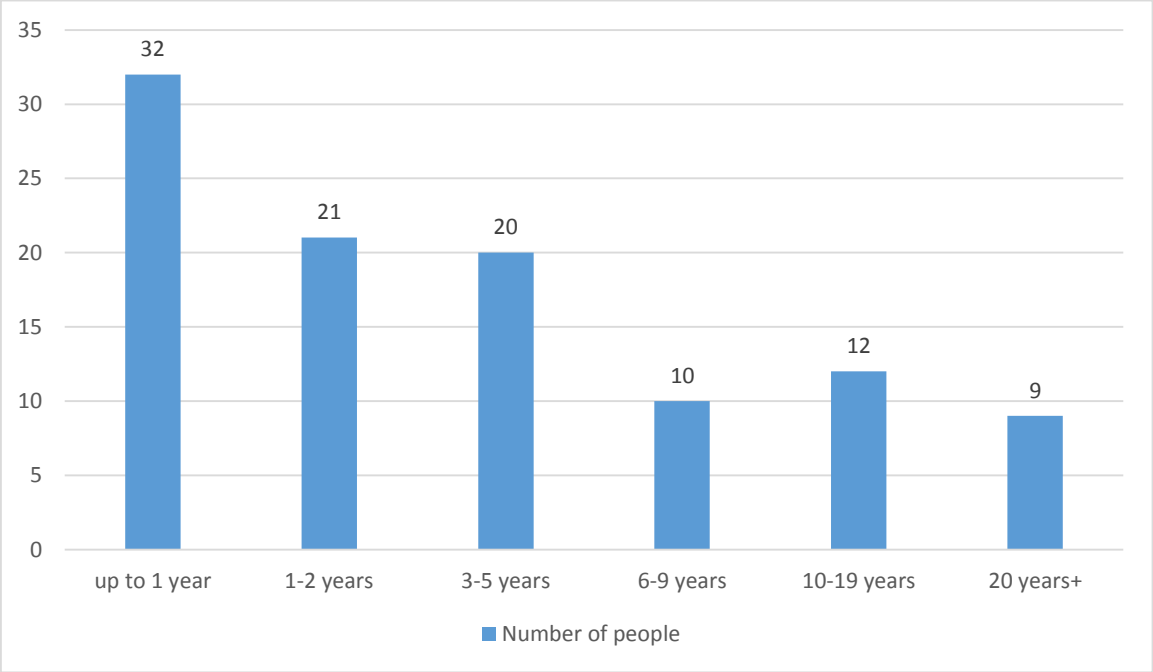
Mental Welfare Commission Report

In February 2016, the MWC published a report, 'No through road', which was based on the Commission's visits to all 18 hospital units for learning disability. They studied 104 people, which they estimate is 50% of the total number affected. The Commission found that 32% of people were "experiencing long waits for discharge". This figure was as high as 46% in Lothian. The reasons for the delay were;

- Lack of funding
- Lack of accommodation
- Lack of an appropriate care provider
- Combination of the above

The Commission undertook a similar study in 2011 and found that 22% of people were delayed. So the position has worsened over the past 4 years with 32% now delayed.

Almost half the people had been in hospital for over three years and 20% for over 10 years;



The 208 people who are the subject of the MWC report are likely to be a subset of the 630 'Category B's' referred to above. This report relates to people with a learning disability whereas the wider group includes those with other disabilities, challenging behaviour, autism etc.

Policy Context

For many years it has been understood that hospital should be a place for treatment where that cannot be achieved at home, or close to home. For all the reasons that are now well understood and documented, people should be admitted to hospital only when necessary and discharged as soon as it is possible, whilst meeting their needs properly.

Against that background, this group appear to have been forgotten. Since the 1980's, strategy has led to reduced long stay bed numbers and the development of a diverse range of service models for people with special needs to live in a community setting. It is recognised that meeting the needs of the most complex and challenging cases will require continuing innovation – but the housing and care sectors are currently providing housing care and support to people with very complex needs and are confident that this can continue. The greater challenge is to ensure that sufficient resources are available for this group. For so long as this group has to compete with less expensive care groups – especially at a time when resources are under such extreme pressure – then those with the greatest needs will lose out. This cannot be fair and that is why we are asking for designated arrangements for this group. If work to prevent or minimise admissions for this group can progress then – in the longer term – the costs of hospitalisation will reduce or disappear.

On the other hand, if the status quo remains, then the current trend of increasing numbers in this position will continue and costs will continue to rise.

Financial Context

We do not believe that people should be living long term in hospital solely because of financial pressures. However, we do believe that – provided a long term solution is put in place as described above - then there will be a positive effect overall on public funding expenditure requirements.

If the Government believes that this 'business case' requires to be made then we would be happy to work with health economists to develop that case.

Conclusions

Good progress has been made in reducing the number of people with complex needs who live in institutions. However, a group of more than 600 people are still living in hospital because there is no apparent alternative. It is likely that this number will continue to grow. This is contrary to longstanding strategic direction which should mean that hospital is used as a place of treatment and not long term accommodation.

The housing and care sectors have come together in the Good Life Group because we believe that many of the people affected could live in some form of community setting. We already accommodate and care for people with very complex needs and want to work with the Scottish Government to find solutions to this problem.

We also want to make sure that, in future, we anticipate the needs of people with complex needs more effectively. This means putting in place systems through which solutions are available so that when existing care arrangements breakdown, a suitable alternative is quickly available.

We believe that the best way of approaching this problem is to see it as a 'one – off'. By this we mean that dedicated arrangements should be made available to provide solutions for those currently affected and also to prevent recurrence of this problem for others in the future. Without such dedicated arrangements, this group is unlikely to be prioritised because of the relatively less expensive needs of other people.

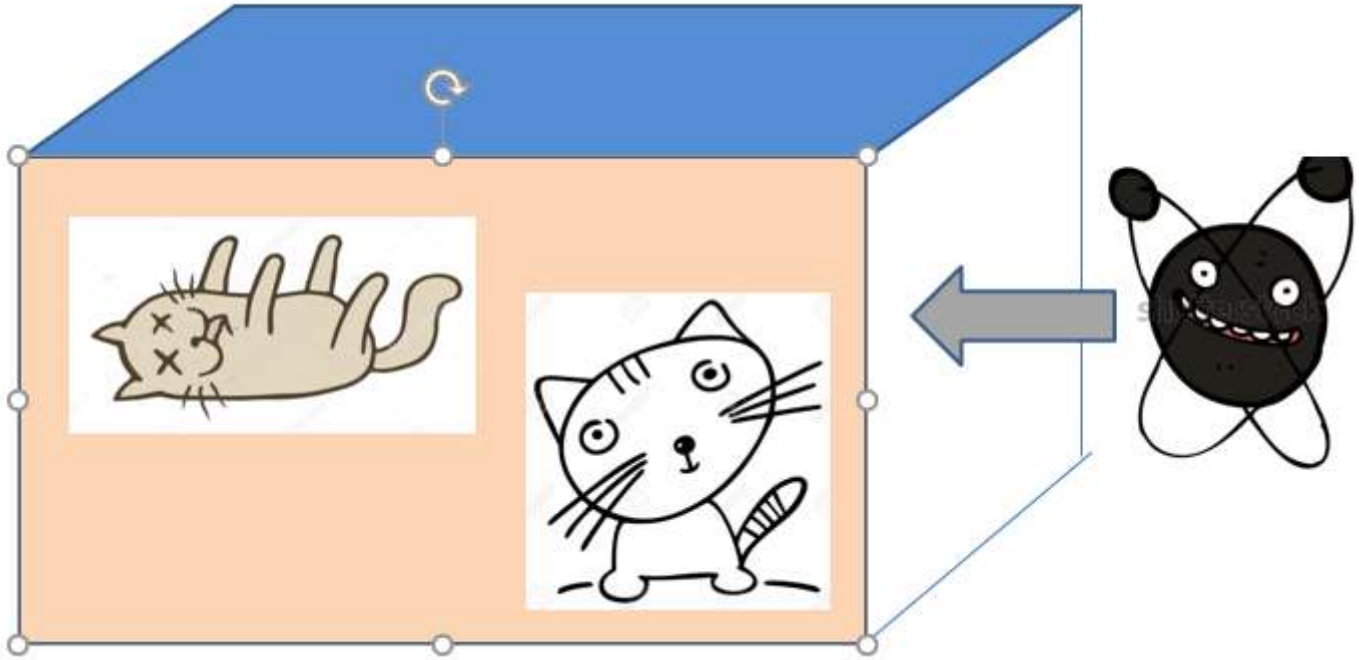
We look forward to working with the Scottish Government.

Midlothian Health & Social Care Partnership

The Quantum Theory of Complex Care

Midlothian Health & Social Care Partnership

The Concept



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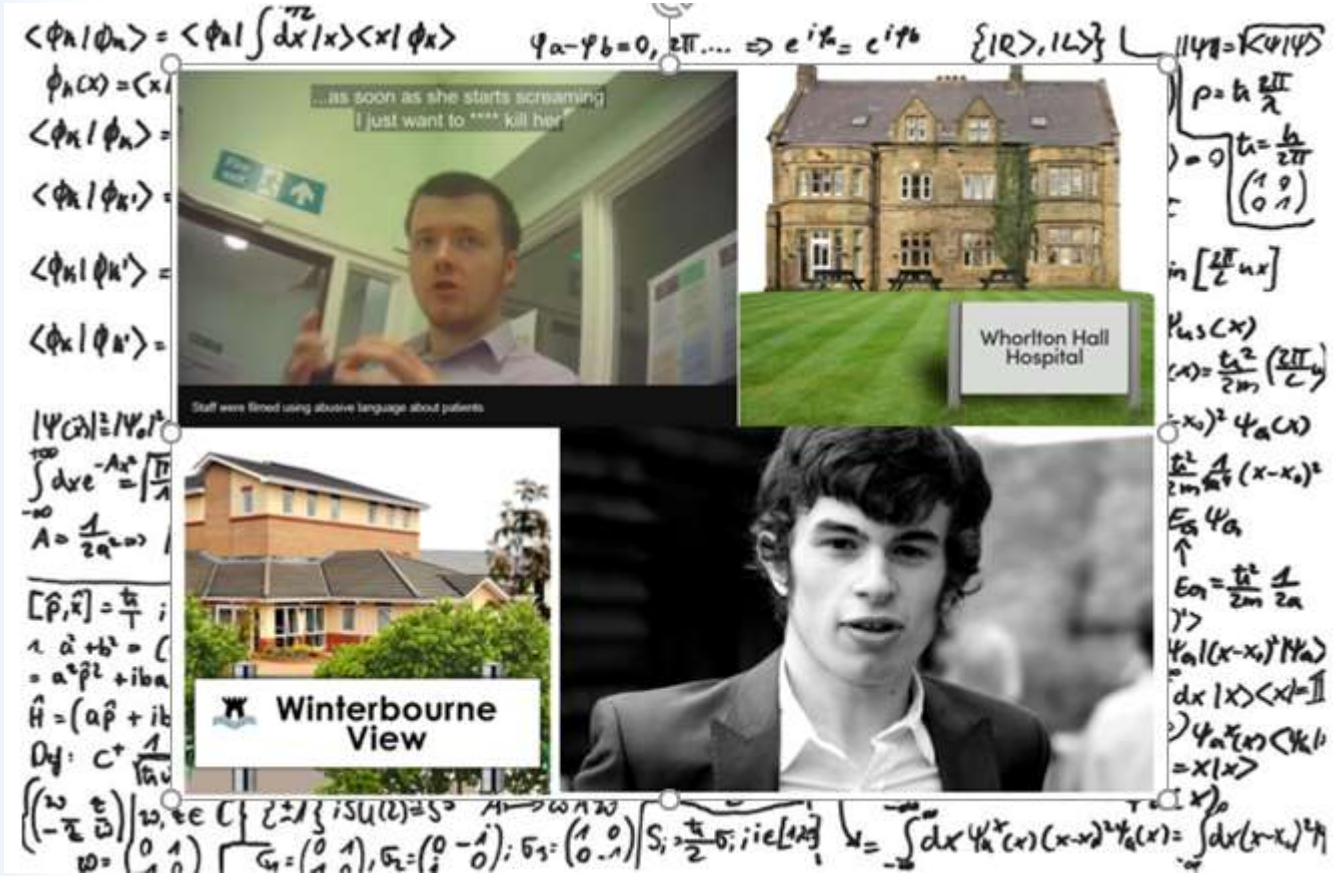
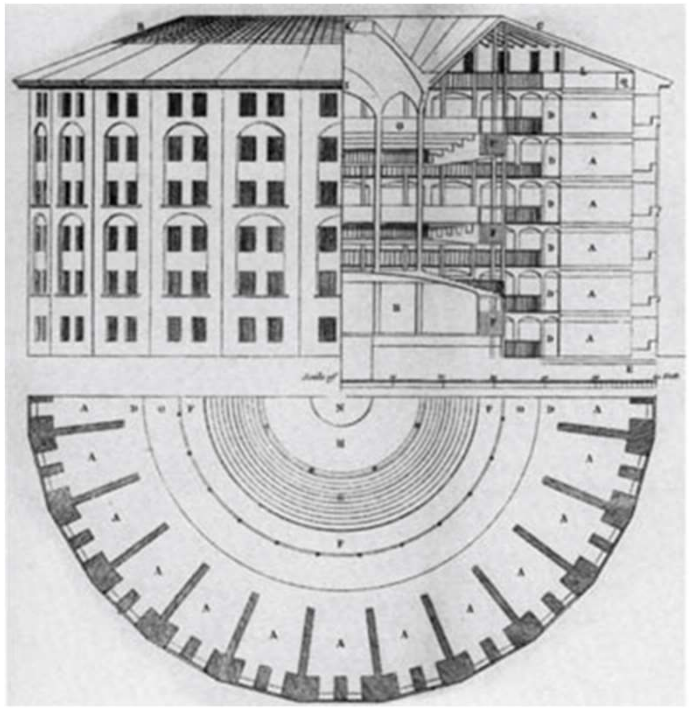
A Disordered Universe



An Ordered Universe

But You May Not Want to Live There

- Campus style a Long Way from Home
- Not too close to any community facilities so no complaints from neighbours
- Good clear view of people's movements
- Standard Robust fittings- last for ages
- Uniformity of design
- Institution with Plenty of shared spaces- Ideal for fights



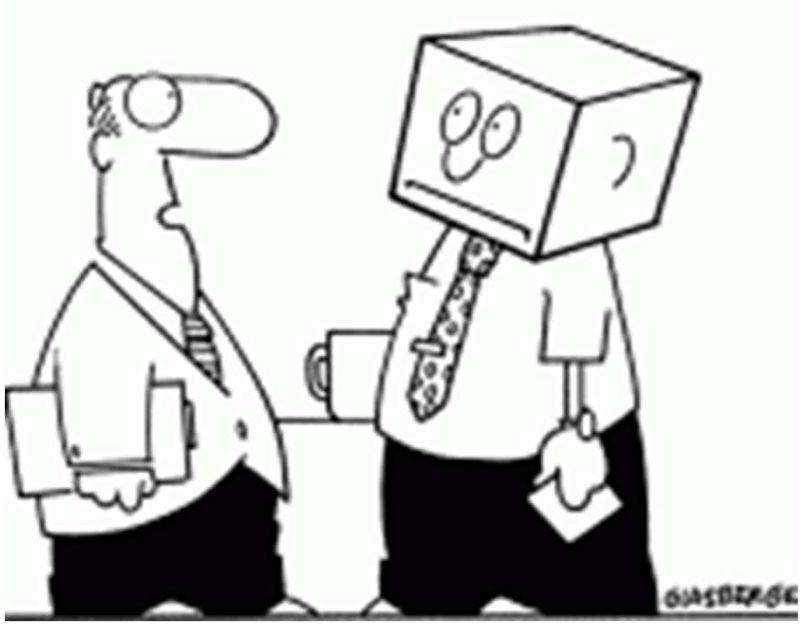
Midlothian Health & Social Care Partnership

You Don't Have to be Einstein to Work It Out

- Ordinary Life In An Ordinary Home.
- Build Upon The Strengths And Skills That People Have
- No Such Thing As A Typical Case
- Positive Behavioural Support
- The Right Staffing Is Critical. Staff should 'LIKE' the people they support.
- Leadership Is Crucial To Success.

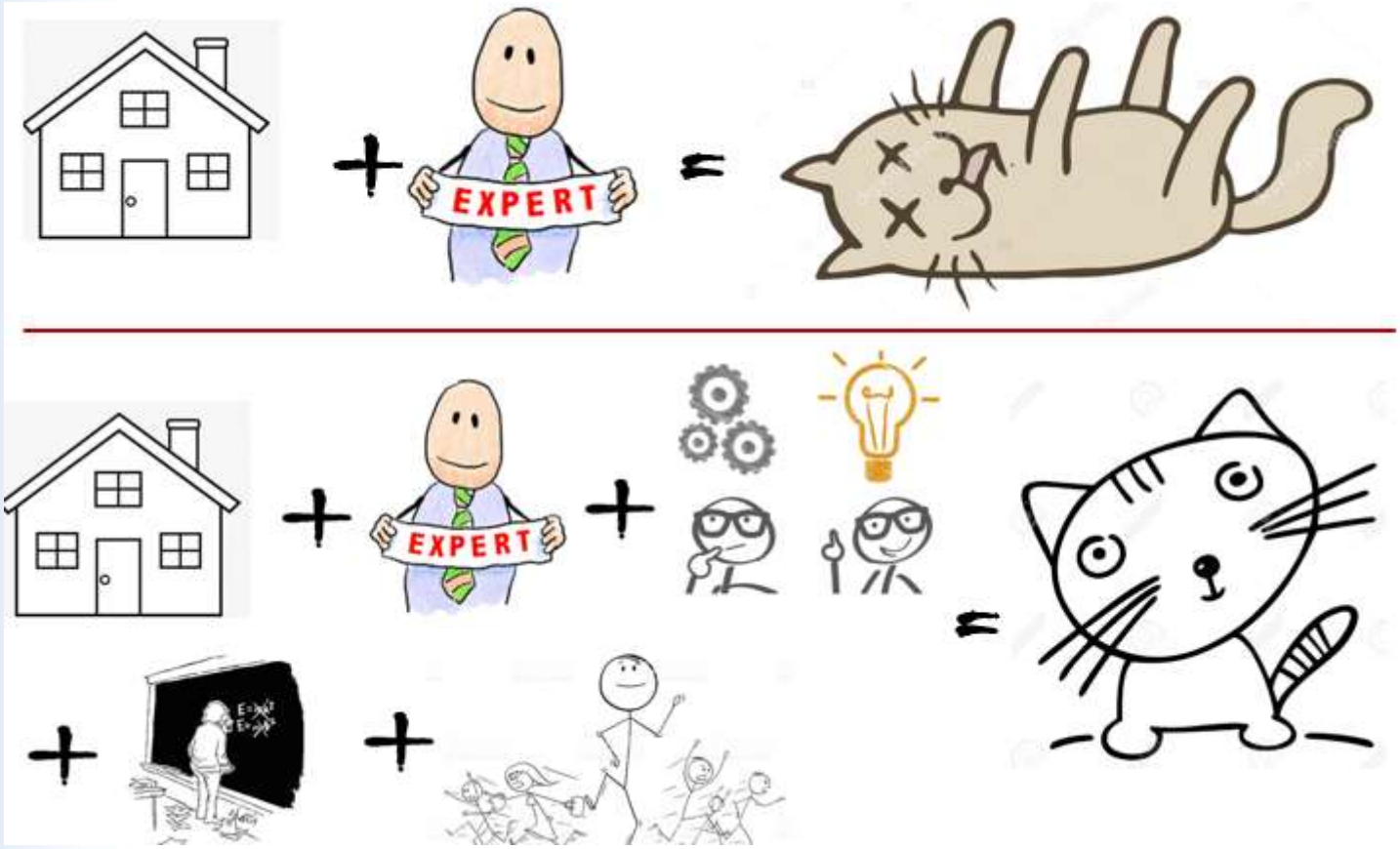
Parallel Universes (32)

It is fundamentally unfair if your opportunity for community life depends on where you live.



The Quantum Theory of Complex Care

Midlothian Health & Social Care Partnership



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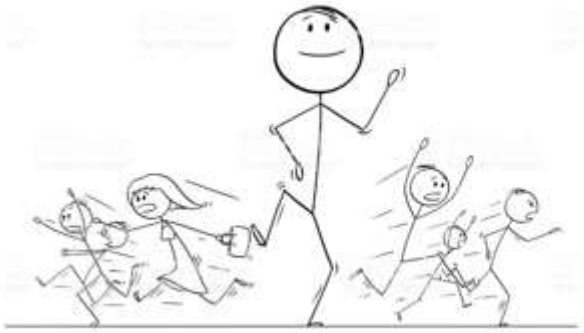
The Fundamental Elements



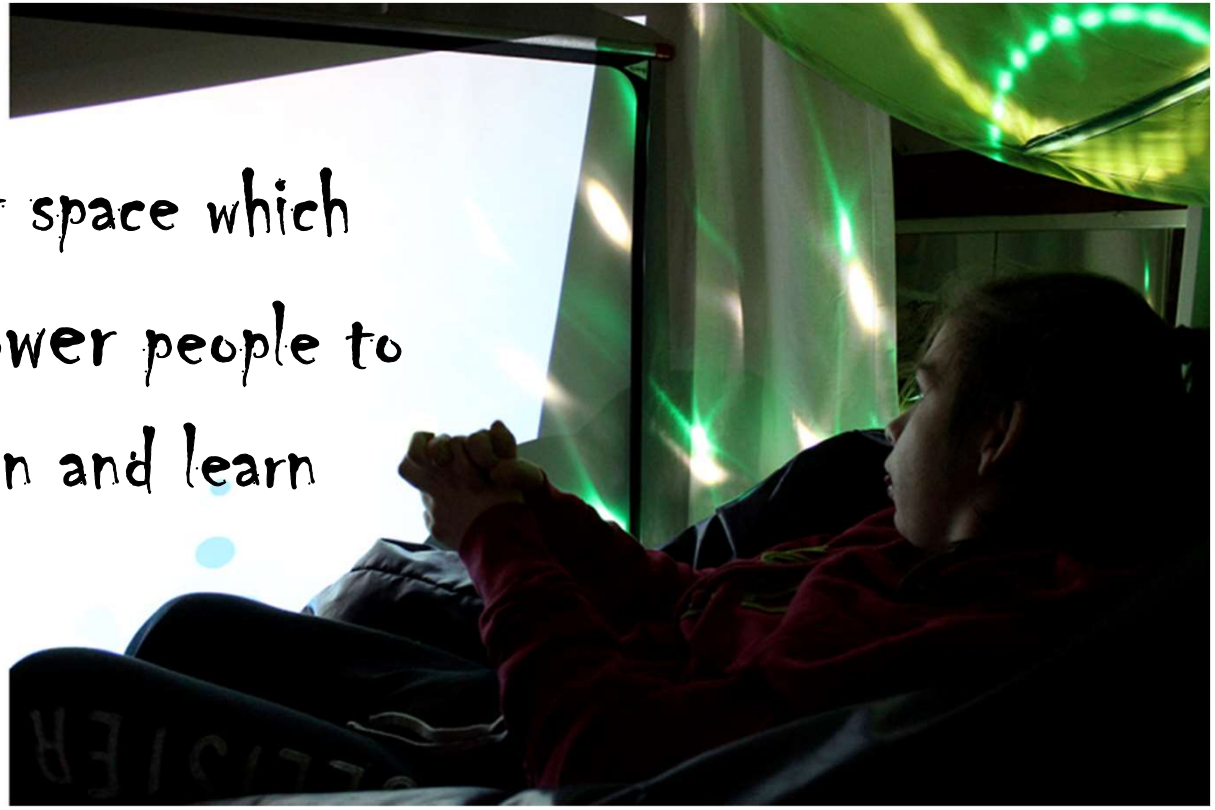
The Elements of Coming Home

Midlothian Health & Social Care Partnership

- Decent Housing
- Flexible Support
- Family Support
- Proactive Planning
- Skilled People
- Leadership
- A Full Life

The Ideas Team and Expert Panels

an independent space which seeks to empower people to take part, listen and learn



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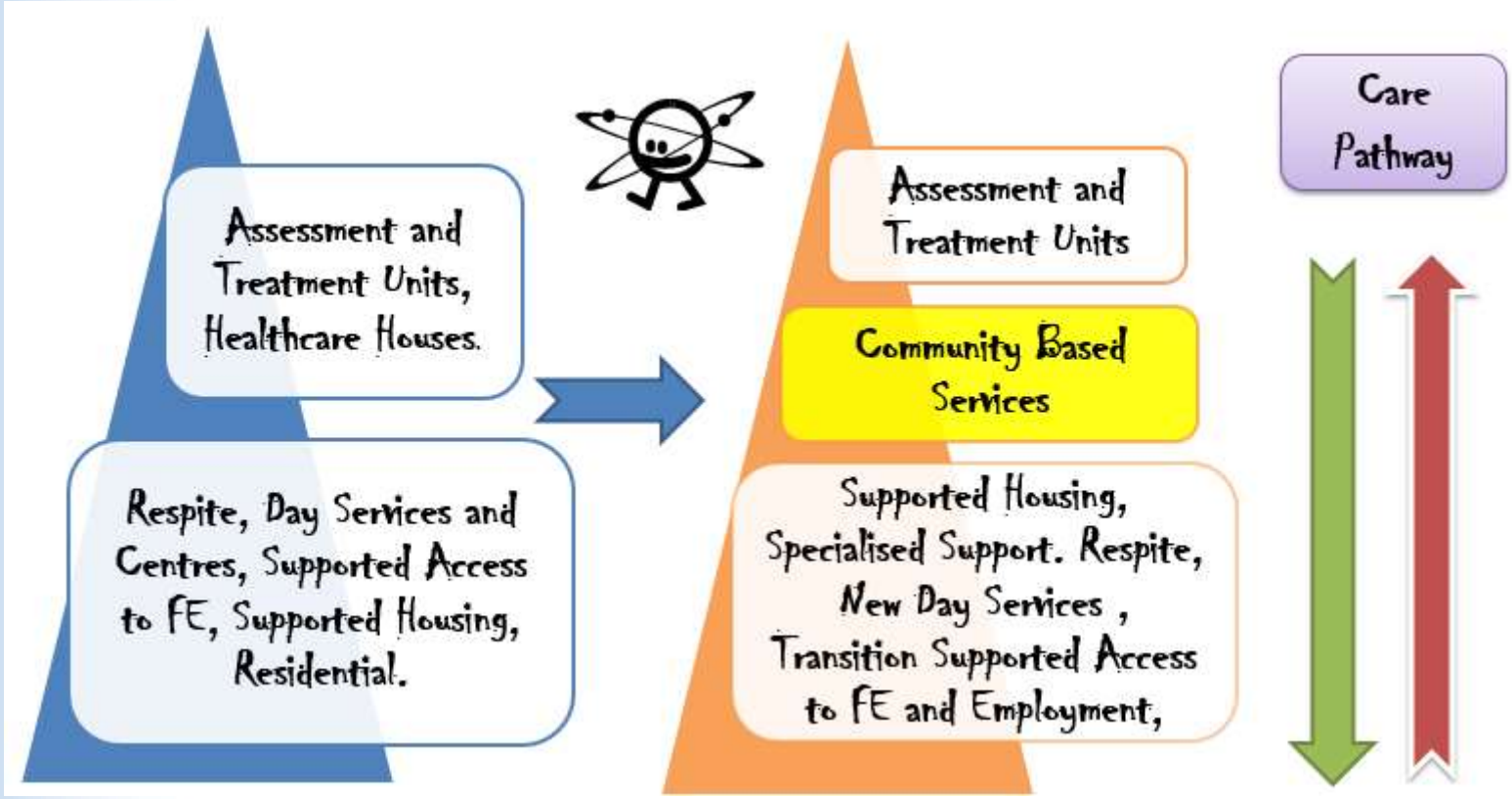
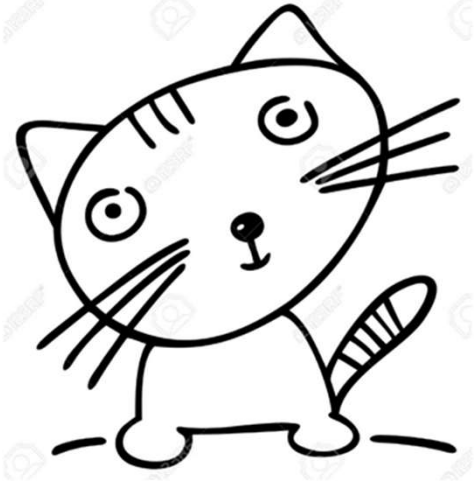
Cold Dark Matter



Known Unknowns

- Human Rights
- Mental Health Act
- Supported Decision Making
- Charter for Involvement
- Transition

?



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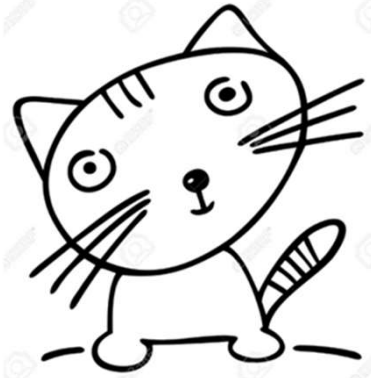
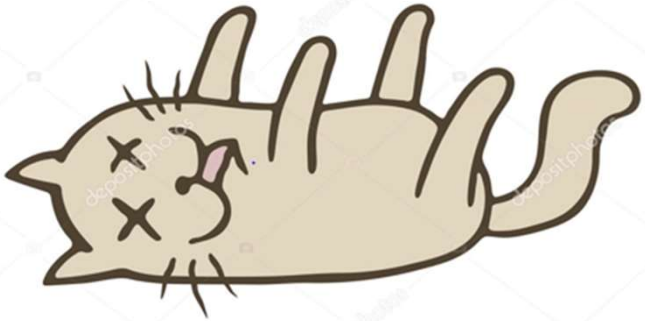
What Planet are You On?

- What's happening in your Universe?
- The Basic Elements
- Good Examples
- Things to Work on





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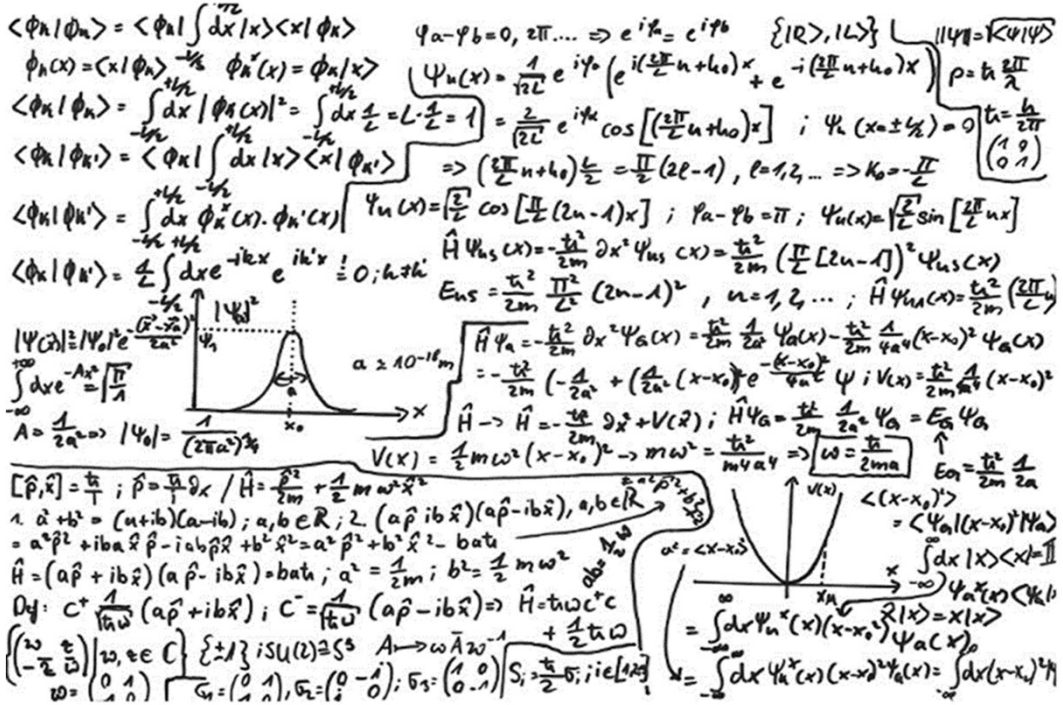
The Solution



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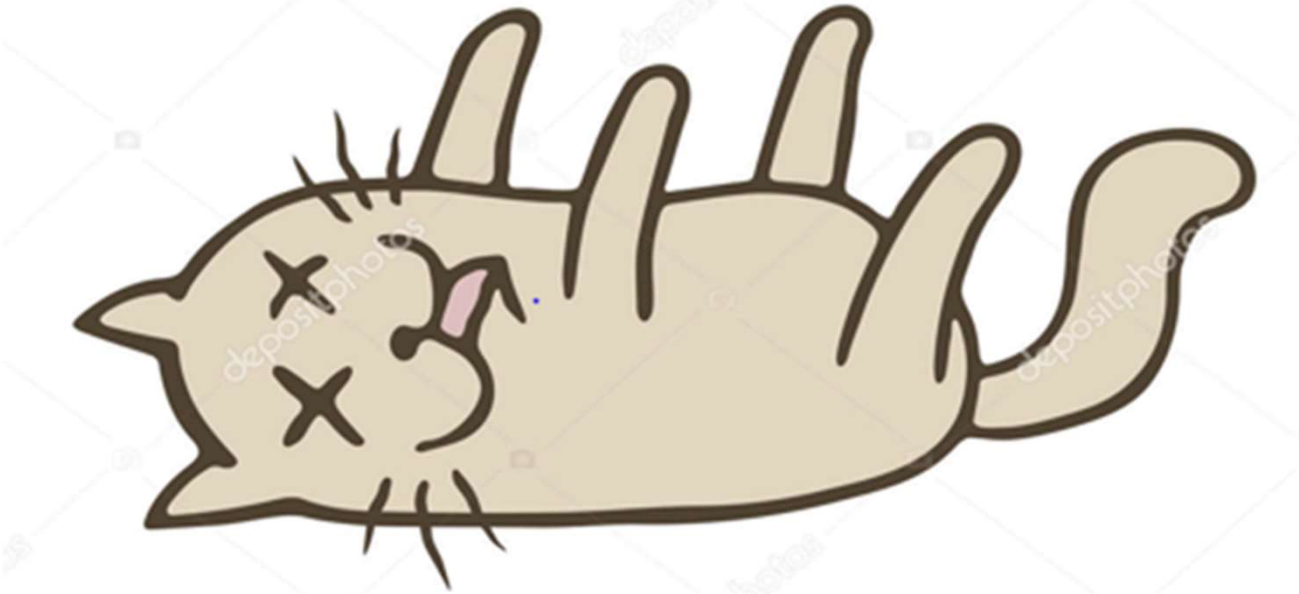
The Quantum Theory of Complex Care- Supplementary Slides for SLWG



Social Work Scotland LD Group

- Many areas have either established some response, or are in the course of doing so.
- Solutions are quite different depending upon factors like population density, geography and demographic.
- Coming Home is a good overview.
- Nobody really has all aspects sorted. I don't think anyway!

Midlothian

- Fastest growing Local Authority in Scotland
- Rapidly increasing population
- Small geographically -9 miles from Dalkeith to Penicuik. So one housing development is local for everybody.
- We have land.
- Close to Edinburgh, issues around recruitment and retention but not as acute as other areas
- Well established LA House Building Programme.
- Location. Town Centre. Demolished a former day centre.

History

- 2013/14- Engagement of Leaders and Elected Members
- Pressure of LD Complex Care
- Lack of Suitable Housing
- Avoidance of expensive and reactive solutions
- Equality and Rights of local people

- Started with 4 Lothian authorities and NHSL but ultimately easier to build it alone. Move to H&SCP has helped.
- Definition of Complex? But we know who we're talking about
- Strong and supportive leadership- recognition of people's human rights
- Relationships/ Housing/ Providers Forum/ Users and Carers
- Other housing to step down is essential and being covered in phase 3.
- First step- build the houses. Get it in the plan. It takes five years.
- Without the properties everything else is compensating for the wrong environment.
- Houses cost 2x usual council house but can be used for anything or independently and design allows for differing needs.
- Safe House

Teviot Court, Penicuik

Design Considerations

- 12 council tenancies
- Core and cluster
- Efficiencies of support
- Town Centre Location
- Twice the size of standard housing
- Nice place for people to live

Design Elements

- high quality environment and support for people who may have been at risk of having to live out of the local area, or of hospital admission.
- 12 in a cluster of four flats around three courtyards.
- Safe, comfortable and homely environment.
- The designs are physically robust, single storey, barrier free and non-institutional.
- The layout is designed in a simple clear manner so that, intuitively, it requires less effort for people with Complex Needs to use and inhabit the environment.
- Centre of community but elements of separation

Finance

- Capital- different approaches considered
- Settled on Housing Revenue Account, Phase 2 of Housing Build Programme plus 50% from General Fund
- Funded by rent charges
- £3 million. £255k from Scottish Government
- Complementary properties in Phase 3 currently being built as part of the house building programme

Commissioning

- Clear Spec based on expertise and thoughtful practice in relation to supporting complex people.
- Understanding of Positive Behavioural Support.
- Competitive Commissioning process. Maybe something more collaborative now?
- Lot of interest. Only one organisation had the real expertise and leadership to deliver. But there are others and orgs are developing this expertise.

- A lot of Research
- PBS on site
- Transfer of resource from NHSL – Local PBS Lead
- Provider Forum
- LD Housing Panel
- Lots of good research on design elements

Now

- Three years in.
- Takes time to embed
- Generally very effective
- Safe House used several times
- PBS expertise developing
- People moving to alternative tenancies
- Dedicated LD Team and Care Management
- No OOA or Delayed Discharge in LD (Today anyway!)

NDTi

National Development Team for Inclusion

Small Supports

an NDTi Programme

A partnership between :
Beyond Limits
C Change
NDTi
Positive Support for You

Supported by:
Local Government Association
NHSE

Note

As a partnership we are not seeking to provide small supports. Our role is to offer information and challenge.

today

- Background
- What are small supports

- We are talking about one loose group of people (people with significant histories, high support needs & ‘hefty reputations’) and one style of support (small supports)

we set out to:

- Understand why we are still failing a significant group of people with leaning disabilities. This group can perhaps best, if clumsily, be described as people with learning disabilities who have behaviors that others have name ‘challenging’ and who need very person centered packages of support;
- Find providers getting it right and the commissioners supporting them;
- Explore every detail of how and why they were getting it right.

reflections on people getting it wrong

Small Supports
an NDTi Programme

Commissioners:

- Lack of knowledge of what good looks like
- Lack of knowledge of how to create good
- Tied to perceived purchasing processes
- Not really person centred in design, provision and review
- Time

Providers:

- Knowledge of good and evidence based
- Traditional values and provision trying to pretend that it is personalised
- Stuck in traditional purchasing models
- Investment/ownership and race for size
- Not developing supports around the individual.

reflections on people getting it right

Small Supports
an NDTi Programme

Commissioners:

- Know what great can be
- Commitment to creating great
- Felt more like ‘old fashioned’ commissioners than purchasers
- Committed to being person centred in design, provision and review
- Time

Providers:

- Knowledge of good and evidence based
- Committed to being great
- Purchased around one person
- Provided around one person
- Lead by social entrepreneurs
- Brave

the gap

Small Supports
an NDTi Programme

- Providers with real skills in providing community based individualised support for people with ‘hefty reputations’
- Return from/prevent admissions to secure settings
- Improve the quality of people’s lives
- Value for money (reducing costs)
- Flexibility

Characteristics of small supports organisations

Making compromises is when things start to go wrong

the individual

The starting point is the individual. This means that:

- From the first steps the individual and family have as much control as possible, with commitment to this control growing
- Starting point is conversation about person's aspirations and needs. Conversations about support, behavioural and risk are essential but follow later.
- Radical changes in aspirations, plans, and supports in the first couple of years. This might have a significant impact on choices made in, for example, housing.

don’t compromise

Once made, the plan has to become the reality. For this to happen:

- Everyone needs to understand that supports can be a platform to people having a life – they are not the life
- Making compromises is when things start to go wrong

staffing

A key element of great support is staffing. This means that:

- Staff recruited around/by the person
- Staff should not be in lots of people's teams
- It is likely that training delivered in more traditional organisations may be of little use and may have to be undone
- Remembering that staff are not a substitute for friends, community peers, coworkers, and neighbours

where people live

It is essential that people are in control of where they live. This means that:

- People choose where they live
- People choose who, if anyone, they live with
- People are tenants, owners or living with family members
- Everyone visiting the person's home remembers that they are a guest

individual funding

Funding has to be available for this to be sustainable:

- All individual services need to be individually funded
- Funding is controlled and used individually

leadership

Small support organisations are created and lead in the right way to offer small supports. This means that:

- There is a committed leader/leadership team who understand how to make an organisation work in a way that supports and does not compromise individual rights and control
- Leaders know and regularly engage with everyone supported
- There is leadership and staffing who understand and work positively with risk
- Funding is sustainable
- The organisation knows and focuses on its community

stay with people

It's essential that we stay with people and recognise that we usually don't get everything right at the beginning. This means:

- We should expect changes and establish ways of learning that support this
- When things go wrong everyone should be involved in thinking about and understanding why.
- By being present in the person's life, the most senior people in the organisation will help to spot potential and address existing issues

be small

Small Supports will remain relatively small, that helps to retain their quality. Thinking about size:

- The focus of the provider is less likely to be people with a particular label than people wanting a particular style of support
- Most senior people in the organisation to know the people supported well
- We suggest that a new provider should not seek to grow beyond supporting a maximum of 5 people in the first year and question its ability to support more than, a total, of 30-50 people well.

create

Small Supports need to be created. For this to happen:

- Small group of identified people to work with and to develop the organisation around
- Commissioners want to work in partnerships outside of the usual practices of procurement
- Funding is available to get the provider started. This will be saved against individual support costs

Costs

Small Supports
an NDTi Programme

- Early analysis finds costs likely to be same or less than an ATU, and often reducing over time
- Even if cost-neutral, what are we really paying for?

Characteristics that support innovation and change

hindering change

- Those in leadership and deliver roles do not have and demonstrate a strong belief in and commitment to people living *meaningful lives* in their community
- Those in leadership and responsible officer posts do not have the time or inclination to develop an understanding of the *needs and aspirations* of the people or how great supports works
- There is a lack of *dedicated time* – both within the week and across the weeks
- Those responsible do not have either a role with the necessary *authority* or an understanding of how to achieve change without authority
- There is a lack of experience of *leading creative change*
- There is a lack of support, engagement and checking from *senior managers*.

promoting change

- People are brave
- A team of people are interested in and given responsibility for developing small supports
- Those involved actively listen to and learn from existing small support providers wherever they are
- There is knowledge of what great looks like and an aspiration to achieve it from a range of partners
- Those responsible have time both within the week and across the weeks
- People in the most senior roles are informed and actively engaging
- There are targets focusing on the development of small support providers, the number of people supported and the quality of that support

things to focus on to create change

- Individual funding
- Funding to the person's changing needs
- Enable the development of small support organisations
- Seek out people to create and lead small support organisations
- Seek out and support housing options
- Activity seek out people to use small support providers
- Engage with and seek the active support of health and social care professionals
- Understand and support what enables everyone in the process to become and remain engaged
- Be brave and encourage bravery

Our activity

To work with local health and social care bodies to:

- Provide challenge and information
- To assist in changing planning and commissioning process
- To assist in finding and developing small support organisations.

To work with new and emerging small support organisations to:

- Provide information
- Provide assistance to emerge, grow and operate
- To challenge on quality

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https://www.ndti.org.uk/our-work/our-projects/alternatives-to-traditional-care11/small-supports/small-supports-20-21-programme

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