



Returning Home

PILOTING PERSONALISED SUPPORT

by **Simon Duffy**



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Foreword



We are grateful to Dr Simon Duffy for his work in bringing together this report on behalf of the Northern, Eastern and Western Devon Clinical Commissioning Group (NEW Devon CCG). This report was commissioned by Gavin Thistlethwaite, the local NHS leader steering the pilot.

The report reflects the determination and commitment of the CCG to develop a system of support for people with experience of a learning disability that is citizen orientated and strengths focused.

This is a brave thing we are doing. There is some uncomfortable reading here, as well as some triumphant stories, and we acknowledge that this is only the start of the change that we need to deliver for local people.

When reading this report we ask that you suspend the temptation to say its wrong or to interpret it as individually criticising you or your part of the system.

Instead, we ask that you focus on what's possible when we work together: to tackle the crisis points for people, to individualise support, to increase people's access to their local communities.

We should let the stories of Peggy and Jane guide us in changing what we do and how we solve the challenges ahead. The next phase of this project will be to evaluate its success. This evaluation will help inform some of the big changes we need to make together in the way that services are organised.

Our thanks go to the people who allowed us to use their stories, to the local teams that helped make these changes, and to those individuals whose belief and passion drive them to design the very best support for people every time.

On Behalf of NEW Devon CCG

SUMMARY

NEW Devon CCG have begun a project of national importance to bring back disabled people and people with mental health needs from institutional services, often 'out of mind' far from Plymouth, and help them to return home. The project was initiated prior to the recent NHS reforms and is focussed on people living within the Plymouth footprint of the Western Locality within NEW Devon CCG.

The individuals in this report have given their consent to their stories being included in this report and they have been anonymised.

The NHS in Plymouth have been working to reduce institutional placements for some time, this report describes the development of its latest project, called the Beyond Limits Pilot. This report is the first of three and it provides an overview of the design of the pilot, its goal and the approach it is taking. Later reports will explore how problems were overcome and what was finally achieved.

The main findings of this report include:

- 1.** In the past, families and individuals have found that a lack of support and the use of institutional placements has been very damaging. Compared to many other places, the NHS in Plymouth has a strong track record in tackling this problem and there appears to be a good understanding of the factors that cause these problems and a desire to do even better.
- 2.** The Plymouth NHS approach to solving this problem build on national and international research and best practice in the UK. The NHS in Plymouth is working with individuals who have a strong track-record in designing high quality, robust and responsive services and is increasing the capacity of professionals and services to provide more personalised support.
- 3.** Early progress is promising. A new organisation, Beyond Limits, has been developed and some people have successfully returned home to Plymouth. There now seem to be better ways of developing appropriate services in Plymouth and the chance to make further improvements.

4. There is still much to do. It is not easy to get people out of institutional services, and new approaches on the ground sometimes demand new approaches within the commissioning system. The opportunity to further improve collaboration between the NHS and the local authority exists, but it will require more work to realise this goal.

The NHS in Plymouth is to be congratulated on leading the way in work of national importance, but building on this success will take the backing of the wider community.

INTRODUCTION

This is the first of three reports, commissioned by NEW Devon CCG, as part of the Beyond Limits Pilot. This report sets the scene for the pilot, explain its underlying rationale and explores the likely way ahead. Although there is some exploration of the current problems this first report is not an evaluation of the project - that is for a future report.[1]

This project was important when it began; but its importance is even greater now that the government has determined to take clear measures to end the reliance of local areas on institutional placements.

The NHS Mandate states clearly:

The NHS Commissioning Board's objective is to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people.[2]

Although much of the attention given to this priority is new and caused by the 'Winterbourne Scandal' it is encouraging to find that the NHS in Plymouth was working to achieve this goal long before that particular scandal grabbed the attention of the public. In fact the strategy of NEW Devon CCG clearly recognises the long-standing problem of institutionalisation for people with learning disabilities.

NHS long-stay hospitals for people with learning disabilities have now closed. However both people with learning disabilities and people with mental health problems often find that they cannot be offered appropriate support in their community. Instead, many people, particularly people with more complex disabilities, find themselves forced into institutional services.

Today, instead of NHS hospitals, these institutions tend to be private hospitals, care homes or assessment and treatment units. The financial cost of these services is extremely high - often as much as £200,000 per year and sometimes higher. The human cost is even higher. Recent scandals represent only the tip of the iceberg for the history of institutional provision teaches us that most abuse goes uncovered.[3]

Although this problem is widely recognised it is rare to find any local area facing up to the problem squarely. This is what makes the project in Plymouth so important, and so inspiring. This project is one of the most important innovations in public services and the NHS in Plymouth should be commended in showing the leadership necessary to bring about the required changes.

If successful the project will have achieved the following outcomes by 2015:

1. 20 people's lives will be better. In particular people will have lives of citizenship, meaning:[4]
 - ◆ More control over their own lives
 - ◆ A better sense of fulfilment and positive purpose
 - ◆ Enough money and more control over their budget
 - ◆ A good home where they feel safe and secure
 - ◆ Practical, high quality assistance from people they trust
 - ◆ A good life, as part of the community, with family and friends
2. There will be a new independent service provider, based in Plymouth, and available to provide support to people with complex needs, called Beyond Limits.
3. In future nobody will be placed outside the city solely because their needs become complex.
4. New models of support will be developed - support will be personalised and will focus on prevention, individual service design and supporting citizenship.
5. New models of supported decision-making, where advocates, family or others are involved in representing and protecting the interests of people who lack capacity.
6. Changes in the network of service providers available, including greater competence in supporting people with complex needs and greater openness to learn and share together.
7. Better coordinated support and communication for families and individuals from both service providers and from the professionals from the multidisciplinary team.
8. Commissioning and funding systems will be more flexible, individualised and responsive.
9. Greater collaboration between health and social care systems and the further development of models of individual funding like personal health budgets
10. The wider culture will have changed, in particular there will be greater belief in the capacities of individuals, families and communities.
11. Much more effective use of local resources, with funding returning to the city, greater efficiency and less waste in the provision of care and support.

In order to bring home people with complex needs, personalised and innovative support will be required at the level of the individual. However it will also demand innovation in commissioning and in the partnership between the NHS and local government.

As Einstein said:

We can't solve problems by using the same kind of thinking we used when we created them.

1. Understanding the problem

Just knowing that a problem exists doesn't make it easy to solve. Sometimes it is easier to ignore a difficult problem. NEW Devon CCG have decided to lead the way by confronting one of the most significant and long-standing problems facing the NHS today - the unnecessary institutionalisation of people with complex disabilities.

This is not just a local problem, it is a national problem. In fact the NHS in Plymouth was already one of the better areas in England, making fewer such placements than most. Now it has decided to go further and to be one of the first to really solve it. But, before we explore how to solve this problem, it is important to understand it.

1.1 Scandal and abuse

Unfortunately there is a long-standing history of abuse associated with institutional services. The recent scandal at Winterbourne View, one of the places where local Plymouth people had been placed, is only one example of what can go wrong. The Care Quality Commission (CQC) did not pick up any significant problems at this service until a Panorama documentary - following up on the reports of an internal 'whistle-blower'.

However when they reassessed this service following the documentary the CQC found:

The people who used the service at Winterbourne View did not receive effective, safe and appropriate care, treatment and support that met their needs and protected their rights.[5]

It is very worrying to reflect that the families whose children had been in Winterbourne View believed it to have been one of the better institutions. The abuse taking place in Cornwall NHS Partnership Trust in 2006 and in the Sutton and Merton Primary Care Trust in 2007 also underlines the prevalence of institutional abuse. There is no reason to believe similar or worse practices are not currently taking place in many of the other institutions where citizens of Plymouth are now placed.

It is to be hoped that this project, combined with the work of the Strategic Health Authority in reviewing the governance around all out-of-area placements, will help turn the tide away from further institutional placements.

1.2 The experience of families

To get to the heart of the problem we spoke to four families whose relatives - all now adults - have ended up in institutional care, many miles away from home. Each talked in detail about their experiences in a group workshop.

Although there were some minor differences, what was most striking was the common pattern experienced by all the families:

1. INITIAL ISOLATION AND LACK OF SUPPORT

All their children had demonstrated, in different ways, significant impairments, difficulties in learning or behaviour that was difficult to manage and many had been subjected to abuse, prejudice and harm from others at a very early age. There were key indicators of problems to come, but no support was available to the families as these problems developed.

2. CRISIS POINT

Every family, whilst caring for their relative, experienced some significant point of crisis. Sometimes this was an illness in the family, sometimes a mental health breakdown, being attacked or, for one family, the disabled person being raped.

3. INSTITUTIONAL PROVISION

The response of the system to this crisis was always institutional service provision. This came in many forms:

- residential care
- residential respite
- residential schools
- hospital
- prison

Families saw each service as a holding space - it was rare that there was any sense of progress or hope:

My daughter just seems to be a head that fills a bed

4. RESISTANCE AND ESCALATION

When the young person was taken away from family, friends and home then typically they would respond with violence, anger or some other form of resistance. This then led to further isolation, increased institutionalisation and a regime of punishment. The first arrangements would break down and the individual would be moved, typically further away from home, into increasingly institutional, expensive and isolating environments.

5. RIGHTLESSNESS AND FAMILY ISOLATION

From the perspective of the family, this pattern of crisis-driven service provision also went together with a denial of the rights of the individual to make their own decisions and the end of any role for the family in advocating for their relative. The use of mental

health legislation to deny individuals their liberty was combined with the absence of any formal role for the family as an alternative source of advocacy. To the families, all power seemed to reside with the service system, but often in an obscure and unclear way that allowed for no accountability.

The trauma for families was increased by some of the common practices in these institutional services. For example families describe how those they love are not allowed to attend the funeral of a parent, or an important family wedding.

When reflecting on these experiences it was impossible for families not to express a sense of sorrow, shame and anger at all that had happened. In particular it was clear that the system's response was damaging to each family in at least four distinct ways:

1. With no early support families were strained to breaking point
2. When the crisis point arrived the only response was to take the child or adult away from their family
3. Any rights to make decisions for or with the individual were removed
4. Maintaining their relationships was made as difficult as possible

Unsurprisingly families felt abused and damaged. They also tended to see their treatment as a form of blame - as if they were responsible for all that happened:

When professionals make mistakes they are never accountable - when a parent makes a mistake they are blamed for everything.

1.3 Real life stories

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Fiona's Story

Fiona is from Plymouth and lived with her family in Plymouth until her early teens. Fiona was a child who needed entertaining and if she became bored got herself into all sorts of mischief.

Throughout her life Fiona had struggled to cope with systems like school and, after a series of failed attempts, in the end she left school. She and her mother Janet were isolated and alone; they had little family support and no additional support or funding from the local authority: "When people promised support they just didn't turn up."

At 15 years old Fiona was placed in a residential care school, living with other children. She was upset and angry and didn't like the place. This placement broke down and she was placed in another residential care unit much further away from home. This time she hit a member of staff and this was deemed 'common assault' and so Fiona was placed in prison at 17 years old.

After prison Fiona was then placed under the care of the NHS using Section 37 of the Mental Health Act. She then went from placement to placement getting further and further away from home, passing through Winterbourne View and other places that

her mum thought were “worse than Winterbourne View.” Today Fiona is aged 26 and is living in the ‘low secure unit’ of a private hospital.

Janet feels that Fiona’s life as a young adult has been wasted. Fiona’s behaviours do not fit into the hospital system. Fiona is not a conformist, she is a freedom fighter. As she is moved to increasingly restrictive units she learns, from those around her, even more negative ways of expressing her anger and dissatisfaction.

During her time in hospital Fiona has had to endure physical and chemical restraint and isolation on a regular basis. When she is deemed not to have complied with the rules of the hospital she is punished and not granted leave to spend time with her family. So she ends up missing important family weddings and funerals.

From the family’s point of view, when the NHS took over, they felt cut out of her life, and when she became an adult they were completely excluded from communication and decision-making. Janet is desperately frustrated at seeing Fiona in a place that she knows is doing her no good, and is in fact harming her even more.

Helen’s Story

Helen has a strong family, but she has also attracted multiple diagnoses: autism, epilepsy and personality disorder. As a child, despite her additional needs, Helen got no extra support. But after school her mum became physically disabled and her father had a heart attack. Her sister became ill and they were told they could not support her. They didn’t want her to leave home, but they had no choice in the matter.

In 1985 Helen went into a residential respite service. This was meant to be “just for one week”. But while she was there she was placed under a ‘section’ and then went on to be placed at a care home. She had problems there and the care home asked for help. She was admitted to a local hospital. Without the family’s knowledge, she was then moved to another care service. Later the family discovered, from a newspaper, that Helen had been abused by the manager in the care service. They felt devastated and doubly shocked that they had not been informed.

When this service was closed down Helen was sent home. But the family were then told they were babying her and she was taken away again to a service hundreds of miles away. Later she was moved to Winterbourne View where she was abused. When it closed she was moved further away again to a private hospital.

Her power of attorney lies with a professional. Helen’s sister has worked hard to stay involved. They try to plan with her and make long distance trips by bus and train to attend meetings, but they have no help from professionals. The family feel completely excluded from decision-making and totally powerless to shape a positive future for Helen.

Mary's Story

Mary has a learning disability and epilepsy. When she was very young, at nursery school, Mary got upset and bit another child. Her teachers began to become afraid of her epilepsy and Mary's education seemed to suffer. However she continued into mainstream schooling until secondary school, then Mary was sent to a special school.

Mary had seizures at night and Mary and her family had no additional support and felt patronised and let down by professional services - although her mum, June was open about needing support to cope. The only support that Mary was ever offered was residential respite care.

Mary was a loving and caring young woman, but she started to become less and less concerned with her own hygiene and she lost the motivation to get up in the mornings to go to college. She seemed to have lost a sense of purpose and a sense of self-worth. The family discovered she was being bullied. At 16 she was attacked and raped by young men in the local neighbourhood. The boys were never prosecuted and Mary was traumatised. Her seizures became worse, as did her behaviour.

Her dream was to move into her own place and so this was what she and her family planned for. However, at 18, now technically an adult, she was placed in a series of inappropriate group homes. (All of the possessions that she had previously purchased for her new flat were taken from her and put 'into storage'. The family still do not know where they are or whether they are safe.)

Mary was first placed with people who were much older than her and she looked after them, but the service could not cope with her behaviour - and so she was moved again into another group home. She didn't like sharing her home, and after a distressing relationship with a man, her behaviour once again became unmanageable for the staff.

She was moved again, this time to a local unit for people with mental health needs, where she again became very angry. She was then moved at very short notice to a service over 100 miles from home. Her mum had no time to object or to try to get the arrangements changed. She felt so distressed by this lack of involvement and control over her daughter's life that she then suffered a severe breakdown and became agoraphobic. She did not have the strength to keep seeing Mary and did not see her again until she visited with staff from Beyond Limits three years later to help with Mary's service design. Their reunion was a very emotional one.

Mary has lost her independence, her skills and her contact with her family. Whilst in these institutions she has experienced violence from others and at one point her arm was broken. In turn she has become increasingly violent and aggressive - especially towards men.

Mary's damaging journey, from institution to institution, has scarred every member of her family. But they are determined to help her achieve her dream of having her own home, near her family, in Plymouth.

1.4 Statistics

An important amount of statistical information is available from both the initial group of people working with Beyond Limits and from the wider group of people in places outside Plymouth.

THE INITIAL GROUP

In this first period Beyond Limits are working with 6 individuals. The professional assessments of these first 6 provide some stark and illuminating information about patterns of institutionalisation. 5 of the group are women and their ages range from 28 to 56. The average length of time spent in institutions was 19 years, with 3 of the group having spent more than half of their lives in institutions. People entered the institutions at a very young age, ranging from 14 to 20. Institutionalised placements last on average just less than 2 years.

On average each person had been in 10 different institutional settings, including:

- ◆ Residential schools (n=3)
- ◆ Acute hospitals (n=3)
- ◆ Residential colleges (n=1)
- ◆ Low secure hospitals (n=6)
- ◆ Specialist facilities (n=6)
- ◆ Residential homes (n=5)

All six had been victims of abuse, including:

- ◆ Neglect (n=2)
- ◆ Sexual abuse (n=6)
- ◆ Physical abuse (n=5)
- ◆ Financial abuse (n=1)

All of these young people had been known to children services, although families reported that support from social services had been non-existent or unreliable. All 6 are part of the Care Programme Approach - a structured system of care management developed by mental health services. All 6 were sectioned under the Mental Health Act (1983) and 3 have been in trouble with the police or the courts at some time in their lives.

OVERALL DATA FOR PLYMOUTH

Currently, in the Plymouth area, the NHS places 43 people outside the City:

- ◆ 17 learning disability placements
- ◆ 26 mental health placement

The average cost of each placement is £168,000 per year, the most expensive cost is £225,000 per year. The average cost is equivalent to £461 per day. It is interesting to compare this to rents and to salary rates. £168,000 per year would allow you to rent a luxurious flat (£12,000 pa) and to pay for one-to-one support at the rate of £18 per hour, for 24 waking hours, for 365 days per year.

NATIONAL DATA

This is not a problem unique to Plymouth. In fact, as Alakeson and Duffy recently noted in *Health Efficiencies*:

Annually, there are 10,000 people placed out of area for mental health reasons and approximately 11,000 people with learning disabilities are also placed out of area per year.[6]

If Plymouth's costs are in any way typical this suggests that there are currently 21,000 people placed out of area in England at a cost of approximately £3.5 billion.

Plymouth has a population of approximately 260,000 people. This means one citizen in every 6,046 is being placed outside the city. However this compares well with national data which suggests that 1 in every 2,619 citizens of England are being placed away from their homes and placed in institutional units. This means Plymouth is performing much better than average at avoiding institutionalisation (43% of the national average rate) but there is still a long way to go, and much more to achieve, as the stories above demonstrate.

The youngest person who is currently institutionalised is 21, the oldest is 76. The average age is 42. The average length of time in their last institution is 23 months (this figure is consistent with the first group of 6). It is also important to note that 10 of the 47 people are women. This suggests men are being institutionalised at 4 times the rate of women.[7]

Overall the NHS in Plymouth is spending £7.2 million outside the city. This is funding that is leaving the local economy. It weakens the social and economic capital of Plymouth, but more importantly it is money which is not being used to strengthen the skills and competence of people in Plymouth who want to ensure the inclusion of people with complex needs.[8]

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1.5 Crisis-driven institutionalisation

The problems that individuals and families face are not the result of professional incompetence or heartlessness. The fact that this pattern of institutionalisation is a national problem suggests that there are deeper, systemic causes. As we have seen, the NHS in Plymouth has a much better record than many other places, however a real and pressing problem remains.

Listening to families, it does seem that there is a pattern of crisis-driven institutionalisation at work:

1. Early problems are not resolved and support is absent.
2. Problems reach a crisis point and statutory bodies are obliged to act.
3. The only response is an inflexible and institutional service, which in turn creates new crises.
4. Placement breakdown leads to further placements, often to increasingly institutional and distant services

This pattern is described in Figure 1.

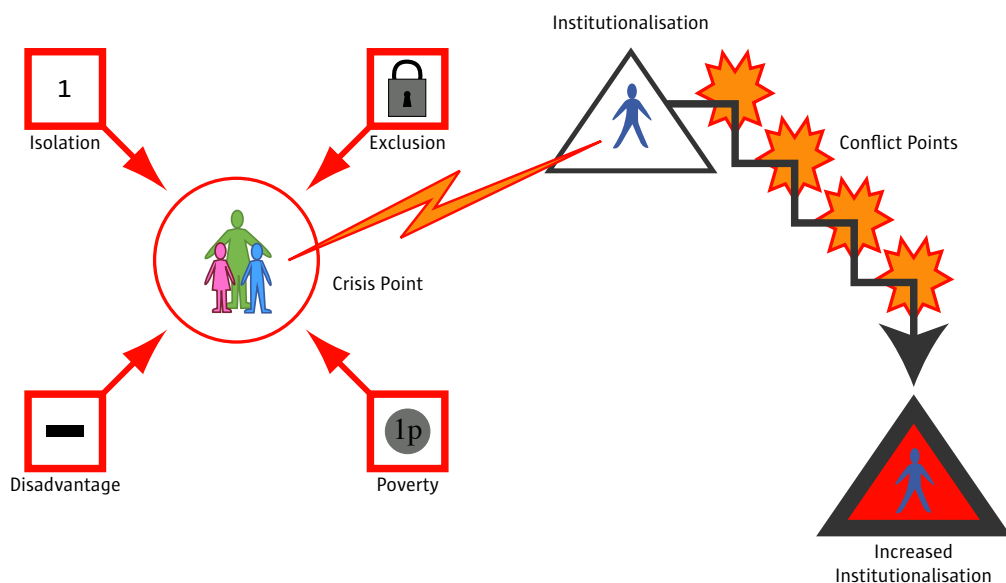


Figure 1 Crisis-driven institutionalisation

Of course, with hindsight, the ideal response would be to prevent the first crisis by offering timely and positive support to families at the beginning. This underlines the importance of collaboration between the NHS and the local authority, for children's social services are the lead agency for providing family support.

However the problem does not only demand better levels of prevention. It is also going to be necessary to strengthen the capacity of support services in the community. Clearly, if organisations and professionals offer inflexible support, then there will be a significant risk that they cannot adapt their support to the needs of someone with more complex needs. Moreover, once a habit develops of placing people with more complex needs into institutional care then local competence at supporting them diminishes. This makes the task of returning people home doubly difficult.[9]

Finally, breaking this pattern of crisis-driven institutionalisation will also require further developments in systems of funding and commissioning. It is vital that funders work to ensure that local development and innovation is supported and that success and competence is rewarded.

2. Developing a solution

The problem of crisis-driven institutionalisation is complex and widespread, however some areas have done better than others and there are many examples of good practice to draw upon. The NHS in Plymouth has developed a plan which draws on the leading examples of good practice and academic research.

2.1 Research

The principles of good practice in this field are well defined. In 2007 Professor Jim Mansell wrote a key report for the Department of Health where he reinforced the key messages, from decades of research and practice.[10] The report describes how commissioners can develop preventative strategies to avoid crises and make the most effective use of available funding.

Professor Mansell's key recommendations were:

1. To invest in local services so they can better understand and respond to challenging behaviour.
2. To provide specialist services locally to support good mainstream practice and to directly serve a small number of people with the most challenging needs.
3. To give priority to improving services for people with learning disabilities with /and challenging behaviour and to demonstrate value for money through improvements in key outcomes: rights, inclusion, independence and choice.
4. To demonstrate value for money by achieving a low number of placement breakdowns, out of area placements and the replacement of low value, high cost institutional services with better community alternatives.
5. To avoid letting families fall into crisis by investing in their support.

The service models that Professor Mansell recommends are also very clear:

1. Individualised, local solutions providing good quality of life in people's own homes and as part of the local community - not services that are too large to provide individualised support or too far from home.
2. The use of direct payments, individual budgets or other systems of individualised funding that enable flexible support.
3. Better communication between the commissioners paying for services, the managers providing those services and the specialist professionals offering advice - to ensure advice is both clear, sensible and successful.
4. Flexible funding made available to enable a wider variety of interventions as an alternative to placement in institutional care.

Professor Mansell also makes clear recommendations on the overall strategy:

1. **Develop partnerships** – work with provider organisations who are committed to developing good services to support people whose behaviours present a challenge to agree commissioning and funding arrangements that will achieve value for money while sustaining investment and the development of local services.
2. **Create service development resources** – identify people who know about challenging behaviour and services, to work with people to implement person-centred plans.
3. **Identify people as a first priority** – focus on these people where problems are serious enough that intervention could make an important difference but where the context is supportive enough to allow the greatest impact.
4. **Develop services** – support the person-centred planning process for these people and deploy resources to implement the plans developed.
5. **Provide back-up** – notice when problems begin to emerge (before crisis) and intervene to provide moral and material support to sustain arrangements through difficult times.

It is clear that these lessons have been taken on board by commissioners and their partners in Plymouth. Their strategy demonstrates some clear-headed thinking and resolve to take the problem of crisis-driven institutionalisation seriously.

2.2 Personalisation

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Clearly the changes required to end crisis-driven institutionalisation are multiple. However the central strategy for the project has been to develop local capacity to successfully bring people back home, to support them to stay at home and to support others to change their practice and culture.

This strategy seems highly sensible. Although it will still be important to deal with the long-term issues of prevention and commissioning, it is the development of local capacity that is the essential first step in finding a successful solution. Unless there are local people who are committed to understanding people with complex needs, and to tailoring bespoke solutions to meet those needs, then too many people will continue to end up in crisis and at risk of institutionalisation.

EARLY MODELS OF ‘COMMUNITY CARE’

After the closure of the NHS long-stay hospitals for people with learning disabilities and the reduction in long-stay beds for people with mental illness, the norm has been to provide a limited range of ‘community care’ services as an alternative to the institution, predominantly:

- ◆ Day centres and sheltered workshops
- ◆ Care homes and group homes

While these services report significantly better outcomes than the institutions they replaced they are typically limited by their own rigid and segregated nature. Supporting groups of people within the confines of segregated services they tend to offer limited flexibility and often take on characteristics that are in fact very institutional:

- ◆ The freedom to shape a life of meaning around one's own gifts is absent
- ◆ Choice and control over everyday life is highly limited
- ◆ Support staff are selected, managed and controlled by others
- ◆ There are many rules and the same rules apply widely to many different people
- ◆ People do not have real homes or real jobs and are absent from community life
- ◆ Beyond their family, real relationships are limited - and these services often limit or damage family life

It would not be unfair to characterise many community services as micro-institutions and the stories from Helen, Mary and Fiona all reinforce this message: they were each asked to fit inside a regime, not a system of support that was designed for them.

However this kind of limited service is not the only option. It is also possible to offer people personalised support - support that is designed for and with the person with complex needs. This supports people to be healthy, safe and well - but it is premised on the belief that good support is focused on the whole person and treats the person as a citizen, with the right to lead a full and meaningful life - on their own terms.

THE DEVELOPMENT OF PERSONALISED SUPPORT

In Scotland, in the late 1990s, the closure of institutions was progressing very slowly. However, by the time the closure process began in earnest some Scottish commissioners, advocacy groups and service providers began to develop a more radical and personalised approach.

Key elements of this approach included:

- ◆ Better and more person-centred planning and service designs
- ◆ Increased use of individualised funding, especially Individual Service Funds
- ◆ Focus on inclusion and rights, including better access to real homes and jobs

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At Lennox Castle Hospital, north of Glasgow the commissioners made a particular effort to develop new services for those people with the most complex needs. Their intention was to avoid the development of the kind of out of area placements that had been typical in earlier de-institutionalisation programmes. Instead, they aimed to ensure that everyone could take their place in the community.

For example, in 1996 a new service provider, designed to deliver personalised support was developed - Inclusion Glasgow. It was highly successful at supporting people with the most complex needs. After it had reached a sustainable size the organisation chose not to grow, but instead to support the development of two new organisations in Scotland: C-Change for Inclusion and Partners for Inclusion. After developing these organisations Inclusion Glasgow also helped to create a wider network of small organisations focused on providing personalised support, which is known as Altrum.[11]

These services are widely cited as exemplars of good practice in supporting people with complex needs. In the foreword to Personalised Support which describes the work of Partners for Inclusion, Professor Jim Mansell writes:

The account presented here illustrates two overarching principles of organisation in Partners for Inclusion. First, everything is referenced to and judged against its impact on the quality of life of the people the organisation supports; this means not only the way staff work, but how human resources, housing, finance and monitoring are carried out and how the organisation is designed. Instead

of expecting people to fit in to arrangements designed for administrative ease, the organisation does its best to design arrangements around the people it supports. Second, there is a high level of attention to the detail of how people want to be supported. Instead of leaving staff to work things out for themselves, risking inconsistency and ineffectiveness, Partners for Inclusion pays attention to thinking through what each person needs and to continually adapting and refining the support provided.[12]

ELEMENTS OF PERSONALISED SUPPORT

Based on the work of Partners for Inclusion, and its sister organisations, there seem to be 7 key elements to providing personalised support:

1. **Commitment to Citizenship** - Above all else the organisation has to commit itself to seeing the people they support as full citizens, people with: rights, potential, full lives to be led and supported. Without this vision and these values then there is a tendency for support to default to unimaginative and limited options. Very quickly this can then create problems by excluding people from the opportunities that give meaning and purpose to life.
2. **Individual Service Design** - Each individual is unique, and so, each support service must be unique. This means helping the person to design support that reflects their individuality, relationships, neighbourhood and future plans. Each design is different, but each design supports the person to express their citizenship - in their way.
3. **Individualised Policies** - Systems and rules need to be worked out, developed and reviewed, at the level of the individual. Universal rules for the organisation are kept to a minimum and only set a framework within which individual policies are agreed. This is the only way of ensuring that people can maximise outcomes and manage risk effectively.
4. **Individualised Support** - High quality personalised support demands that people get support from the people who are right for them. This requires a radically different personnel policy to that typically found in public services. It is much more about values, personality and interests than formal qualifications. However Partners for Inclusion do work to the rules defined by the Scottish Social Services Council and meets all their requirements.
5. **Individual Funding** - It is impossible to provide flexible support to individuals if their money is used to fund blocks of services. Personalised support requires organisations to use Individual Service Funds to manage and protect people's individual budgets and to ensure that money is used flexibly for the best possible outcome.
6. **Power with the Person** - Each arrangement must ultimately be authorised by the person themselves or by those who can stand by the person and help them make the best decisions for themselves. For the organisation this means involving the individual, their family or other representatives in all critical decisions that concern their life.
7. **Creative Community** - All these systems only come to life when they are used by a real community of people - both inside and outside the organisation - who can think creatively. This demands real value-based leadership and the development of trust based upon real understanding of needs and problems.

This model of personalised support is described in Figure 2.

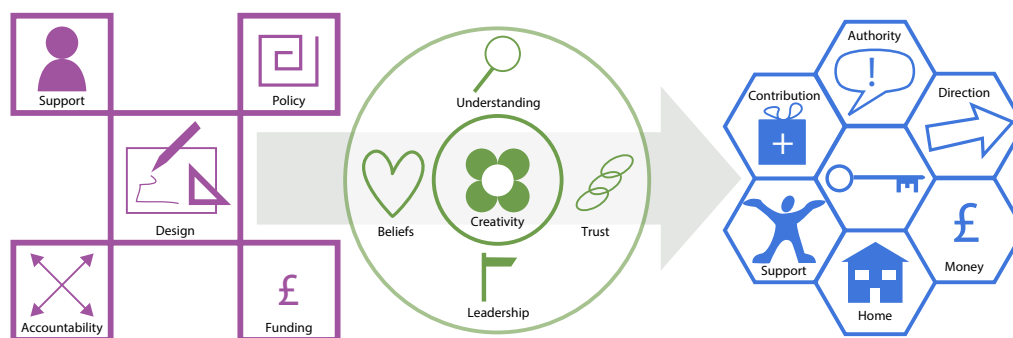


Figure 2 The elements of personalised support

2.3 Developing capacity in Plymouth

The NHS in Plymouth decided to build on this model of personalised support by developing a pilot project and commissioning a similar organisation in Plymouth to deliver the project and to encourage wider organisation learning.

CREATING A NEW ORGANISATION

Creating the capacity to work in a very different way is not easy. Simply changing policies, language or commissioning guidelines is unlikely to be successful. It is impossible to achieve high quality care simply through contracts or regulation. Real organisational change requires leadership and strong values.

In order to develop an appropriate organisation for Plymouth the NHS commissioners approached Partners for Inclusion and asked for their support. Partners for Inclusion believes that small, locally-based organisations, are more likely to offer the best support and they agreed to work with the NHS to establish a new independent organisation based in Plymouth - Beyond Limits.

The leadership of the new organisation is based on a partnership between Doreen Kelly (the CEO of Partners for inclusion) and Sam Sly a local professional, with a track-record in supporting people with complex needs. Together they lead the organisation, while Partners for Inclusion offers not only a template for good practice, but also a range of practical supports to help the organisation get off the ground.

Building on this mix of local leadership and a well-tested model, the NHS committed itself to support the organisation's development. The organisation would be funded by bringing people with complex needs home to Plymouth. Over three years the process would not only pay for itself but would also provide some significant savings to NEW Devon CCG (approximately 10%).

In addition Beyond Limits would work to develop a local alliance of services, called N-Compassing to enable them to offer similar supports.

The commitment to develop this pilot now seems particularly fortuitous, given the discovery of abuse at Winterbourne View and the greater priority given by central

government to reducing institutional placements. However, it is worth noting that this policy was developed well in advance of that particular scandal and reflects a long-standing commitment to help local people return to Plymouth with appropriate support, and to increase the efficiency and effectiveness of local commissioning.[13]

A NEW WAY OF WORKING

Building on the model of personalised support described above, Beyond Limits uses the following tools to provide their support service:

1. **Person-Centred Plan** - this identifies what the individual wants to do and what they are able to offer in their communities. The aim is to help the person share their own individual gifts, skills and talents so that they become valued and respected citizens.
2. **Individual Service Design** - this describes the kind of support the individual needs. It is developed with the person and those that know them best. It must be put together before the person is supported and includes all the necessary details for a tailor-made service.
3. **Working Policy** - this describes exactly how to work with an individual successfully. It helps the individual, family, paid staff and professional experts to agree on exactly how to reduce risks and keep the person and others safe.
4. **Individual Service Fund (ISF)** - this is the person's own individual budget which can be used flexibly to provide the best possible support. The fund is restricted to the person, subject to any agreed management costs. The individual and their family (where appropriate) have the maximum degree possible of control over that budget.
5. **Home of your own** - this is the person's own place. Although there is no presumption that people must live alone, it is critical that it is a place where they feel safe, in control and is a base for their own life. Nobody would be forced to live with someone else.
6. **Personal Team** - this is the group of paid staff that supports them. They are recruited just for the individual. The individual has the maximum degree of control possible over their own support and people should not be over-supported when they can do things for themselves. Other forms of support, natural support or assistive technology, could be part of the service design.

PERSONAL HEALTH BUDGETS (PHBs)

This project is also an important opportunity to test and strengthen wider commissioning competence. Effectively this system is a form of individual budgeting, similar to the model being developed by the Department of Health and called Personal Health Budgets (PHB).[14] A PHB is a payment from the NHS direct to a service user, for them to use in commissioning their own personalised support arrangements. The budget can include funding for all, or a portion of, an individual's support or treatment needs.

Using an ISF - a provider managed budget - is one important mechanism for managing a PHB.[15]

For commissioners and for providers it creates important opportunities to increase the quality and efficiency of services, especially for:

- ◆ Children and adults with complex or continuing health care needs [16]
- ◆ Adults with dementia
- ◆ People with mental health problems [17]
- ◆ People needing care at the end of life [18]

It is to be hoped that the commissioning of this pilot, and the learning that this will provide through its implementation by Beyond Limits, will thereby help NEW Devon CCG to explore the possibility of extending this innovation further in the future.

2.4 Wider developments

Not only will Beyond Limits be responsible for providing personalised support they can also work with other local services to strengthen capacity and competence across Plymouth. The goal is to set up a good practice sharing forum in Plymouth with like-minded organisations. For example, bringing together leaders from within local services in two workshops it was possible to identify some of the key elements of a better system.

PREVENTION

People with complex needs are often easily identified and supported within our community, as children, young adults or later in life. Healthcare services, schools and other services for children are already likely to be in touch with the family. If these services worked differently and had the capacity to trigger flexible, low-cost supports much earlier then problems could be reduced.

There is also a strong case of investing in a system like Local Area Coordination, or different forms of social work practice, that make prevention and community support the central objective.[19] This is an issue where a joint approach by the NHS and local government is essential.

CRISIS MANAGEMENT

When things go wrong there is sometimes insufficient capacity to respond quickly and flexibly. Often clinical expertise get applied too late. The only services that seem to have spare capacity are the services that take people out of their community. The failure to respond quickly and flexibly also creates fear, anger and panic. This further drives inappropriate solutions.

Better crisis management will require changes in commissioning and care management (social work, nursing, care co-ordination and clinical leadership). Currently responsibility is diffuse, systems are confused and yet inflexible. Again, a more coordinated approach between the NHS and local government is likely to help reduce problems.

FLEXIBLE SERVICES

Although there is much good will amongst local services, and a real desire to improve practice, there is also acknowledgement that local services - particularly when they are commissioned too inflexibly - have not always been competent in responding to people with complex needs effectively. The historic pattern of commissioning forms of residential care and day services has led to a lack of competence in creating bespoke solutions for people with complex needs.

In addition, developing models of better practice requires a culture of sharing information, learning and experiences which has been undermined by the organisational behaviours that have developed in response to competitive tendering. There are of

course solutions to these problems. Personalisation opens up new possibilities and new approaches to competitive tendering are also possible. In addition organisations can, with time, build more trusting and collaborative relationships.

STRATEGIC COMMISSIONING

The long-standing problem of crisis-driven institutionalisation exists at the critical interface between the NHS and local government.[20] Crises require clear leadership and no confusion about responsibility.

As it stands there are inherent tensions in the relationship between the NHS and local government.

1. As the complexity of needs seems to increase then the pressure to treat those needs as 'healthcare needs' also increases, which puts pressure on NHS budgets. Quite naturally the healthcare system may respond by increasing the eligibility threshold. However this can create a perverse incentive to allow people's problems to increase in magnitude until they are eligible.
2. As the complexity of needs seems to reduce then the pressure to treat those needs as 'social care needs' also increases, which puts pressure on local authority budgets. Quite naturally local authorities may resist having to accept additional financial responsibility for services that had previously been funded by the NHS.

Together these two forces create a ratchet effect: it is much easier for costs and problems to escalate, much harder for costs and problems to reduce. However, this problem can be managed. The relative success of Plymouth in reducing the level of institutional placements, compared to the national average, demonstrates that competent local leadership can make a difference and can take appropriate shared responsibility for their decisions. But the personal responsibility necessary, at every level, to make this work is critical and problems will grow if there is not a constant effort to build on past progress and to further strengthen shared responsibility for the underlying issues.

RIGHTS

From the perspective of families and individuals many of the problems that create institutional placements can also be seen as a problem of rightlessness:

- ◆ The lack of any early form of self-directed and preventative support
- ◆ The rapid loss of control over decisions when problems occur
- ◆ The inability to commission personalised solutions
- ◆ The lack of accountability and confusion of roles

When local citizens with complex needs and their families begin to feel more in control and better understand their rights and responsibilities this will be the best indication that the proposed solutions in Plymouth have had a real and lasting affect.

3. Early progress

It is not unusual to find that the early stages of any pilot include a mixture of progress, set-backs and unexpected delays. The Beyond Limits Pilot has experienced its fair share of all of these, but overall it is clearly making progress. Later reports will review some of the developments in more detail.

What follows is a brief overview of the early stages of the pilot.

3.1 Creating a new organisation

Planning for the Beyond Limits Pilot started in the summer of 2010 and the organisation, which is a technically domiciliary care agency, began to function in July 2011 and supported its first person in November 2011. Much of the delay in starting due to the length of time that the Care Quality Commission (CQC) took to register a new service.

The process of organisational development involved the NHS giving Beyond Limits a grant so that it could provide a brokerage service. This meant Beyond Limits would:

- ◆ Meet and build relationships with individuals and families
- ◆ Develop an individual services design and working policy,
- ◆ Only provide services if Beyond Limits won the subsequent tender

This process has been successful in enabling the development of a new organisation, and it also creates new opportunities for other services to provide services.

However the process also seems to have extended the process by which people return home. The process could be quicker, less expensive and less confusing for families and individuals. However this would require some further developments in commissioning practice, which will be explored in the next chapter.

3.2 People's lives

There are now four people who have returned home. A full evaluation of people's change in lifestyle will come in later reports but early signs are promising.

First service: Peggy

As is often the case, the first support service provided by Beyond Limits is probably atypical and reflects the need to quickly respond to changing circumstances. Peggy, unlike most people in the study, was not detained under the Mental Health Act and she was outside the scope of the original six people identified to work with Beyond Limits. However rapidly changing circumstances demanded an urgent and flexible response.

Peggy was living a long way from Plymouth in Rose Villa, the 'step-down unit' at Winterbourne View, in Bristol. When the revelations of abuse at Rose Villa hit the press and photographers started to camp outside her bedroom Peggy decided to leave, and she left quickly. She got the train back to Plymouth, was sent back to Bristol, and then got the train back home again. At first many thought that she wouldn't want to return to Plymouth; but this is where she moved - to be with her family.

Beyond Limits had just been established when all this happened. However, thanks to a good partnership with another local agency, Havencare, support was provided to Peggy until Beyond Limits could take over.

- ◆ Peggy is now in touch with a big part of her family again, spending time with her Mum daily.
- ◆ She has started to take control of her medication, her own money, and her daily plans.
- ◆ She booked herself ice-skating lessons, with her own money.
- ◆ She has been clubbing, gone on holidays and visited friends in Bristol and Cardiff.
- ◆ She chose her own staff.
- ◆ She has her very own flat furnished and painted by herself and people within the community that have befriended her.

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Already there have been lots of changes. She is finding her feet, thinking of moving, and thinking of living with someone else. She is more confident, more able to say no, and her health is more stable. She smiles most of the time.

The complexities and problems in Peggy's past have meant that it has been critically important to develop a set of rules and support structures that can enable Peggy and her supporters to manage without over-reacting and triggering further problems. It has also been important to establish a more respectful relationship with Peggy's wider family and to avoid blaming them for problems that may arise.

Second service: Jane

Jane has a moderate learning disability. She was bullied at school and she was sexually abused by her father. After this happened her mother Lauren and her sister Sarah came to Plymouth to get away from him. Jane was then bullied throughout her schooling, and her sister had to protect her. After school Jane's daily structure fell apart. She tried a few jobs, but without support these failed, she slowly started to spend more and more time on her own and drank, smoked and self-harmed. She also became pregnant, something that she had always wanted to happen. But, feeling unable to care for her child, Jane and her Mum decided on a termination.

After this Jane became extremely depressed to the extent that she was admitted to a NHS mental health hospital. Mum and Sarah had asked and asked for support for Jane,

desperate about her declining health and unable to do anything about it, other than care for her as they always had.

Jane moved to a group home in Plymouth but Sarah thinks the staff did not know how to support Jane and she was given too much freedom. The family were often asked to come in and help when things went wrong for Jane.

Once again Jane became depressed and attempted to walk into the road in front of a car. She was moved to Winterbourne View. Jane stayed for 2 years in Winterbourne View - where she quite liked the degree of structure, the lessons and the routines. She was then placed for 3 years in a local mental health service.

Sarah described this as a crazy place which didn't work for Jane and merely acted as a place of containment. Any problems with Jane quickly led to the police being called and she ended up having to go to Court and was given a suspended sentence. All of these experiences have left Jane with increasingly fragile mental health. She hears voices telling her that she is horrible. She desperately wants a baby and her self-esteem is very low.

Sarah says that all they have wanted is for Jane to have a place of her own, near them, so that they can continue to be a close family. But they have had to fight every one within the system every step of the way to achieve this for her.

Jane and her Mum picked her Beyond Limits team. Jane enjoyed interviewing them over a drink in the pub. Her team started to get to know her through shadow shifts in care service, until she was ready to move.

Jane now has a home of her own which she has furnished and decorated with the help of her family, friends and her team. Jane is slowly starting to get used to doing what she wants to do every day. She has been to Newquay on holiday, and bought herself a new wardrobe of clothes that fit her. She bakes and has cooked dinner for her mum and sister. She still has times of feeling down but slowly Jane is starting to see that her life can be a good one from now on.

It is still early days for both Peggy and Jane. Often old problems bubble up after weeks or months. However early progress is promising.

3.3 Family experience

Another promising sign is that the families of people still in institutions are reporting very positive experiences of working with Beyond Limits in order to develop service designs and prepare those they love to return home.

These are some direct quotes from families:

Beyond Limits are interested in the real person - not just 'heads on beds'

They look at the overall picture and try and find solutions

They seem to really welcome the involvement of families and communicate well with us

They show real understanding of what's going on in my life

It was so refreshing to see, that when the institutions were hostile, Beyond Limits just stood their ground.

They look for the full facts - they don't let people push things under the carpet

The person is really involved - they can become a teacher

It's the first time someone's listened to the person - they were smiling

It's the first time the person has been able to stay the whole way through

It's the first positive thing to have happened in 30 years

Developing a supported decision-making agreement really helped

But families are not naive. They are also aware that this is early days. They have been let down many times in the past and it takes time for trust to develop. They are still very aware that power and control still lies in the hands of commissioners and professionals. For the families the current tendering process is particularly stressful and slow - adding further uncertainty where clarity is required. People are desperate to get out - but are very aware that the threat of the 'section' or prison still hangs over their heads.

3.4 Increasing collaboration

A new group for service providers, called N-Compassing has been established in order to support provider developments in Plymouth. This group has three initial founders Beyond Limits, NewKey and the Michael Batt Foundation.

The aim of the group is to eventually form a community interest company that will give small providers the opportunities that larger providers have had: to develop good practice, share experience and knowledge, share resources, share training, reduce costs and influence decision-making with commissioners.

Key people in the organisations have met several times and slowly the organisation is starting to take shape. N-Compassing is working together to help service providers align their induction and training processes so that they are more efficient and can be more quickly accessed by all their staff.

4. Challenges ahead

So far the project appears to be succeeding in its central task. People are returning home and being successfully supported in the local community. Individuals and families are experiencing a much higher degree of influence on the design of services and a much greater sense of control over those services.

If this momentum can be sustained then the project is likely to achieve its short-term goal of helping move back home increasing numbers of people and developing a new service provider. In addition early efforts to share expertise and learning between local service providers seems to be having a positive impact. If this is linked to developing commissioning practices then there should be many more local organisations that are competent in providing high quality and flexible personalised support.

However there are at least 3 significant problems that need to be tackled:

1. Protecting human rights of individuals
2. Increasing the efficiency of the process
3. Strengthening strategic commissioning

1. PROTECT HUMAN RIGHTS

It is natural that once someone is placed, at great expense, in an institutional unit - often privately owned, the institutional unit will not lead the process of resettlement. Anyone with practical experience of resettlement knows that there a host of measures that can be taken to slow down and obstruct someone's successful return home.

Nevertheless, if the following partners are of one mind then a successful return is achievable:

- ◆ Individual
- ◆ Family
- ◆ Service provider
- ◆ Care coordinators
- ◆ Commissioners
- ◆ Clinicians

However, running through this list also highlights one of the further difficulties of resettlement. Whilst it takes a few people, acting at a point of crisis, to place someone in an institution, it seems to take much longer and to involve many more people to let someone return home.

It is critical that the process for decision-making is clear and does not cause undue delay. Key elements of a sensible solution would be:

- 1. Clarifying representation and advocacy** - Good practice in mental capacity would ensure that anyone needing some representation had a reliable advocate or representative. Family members are often the people that are chosen by the person and there needs to be a good reason for any person's preference to be overruled.
- 2. Clarity in decision-making process** - If the service provider believes that it has a competent plan to help someone return home, and this is supported by the person or their representative, then this should lead to a clear and efficient decision-making process. If the institution or any professional wants to provide evidence that any such plan is inappropriate this must be done in a timely fashion, and commissioners must review the evidence together with the proposed plan. Endless delays based on a desire to please everyone involved are unlikely to do anything but increase risk, cost and anxiety.

The spirit of mental capacity legislation would suggest that effective decision-making should support the best interests of the individual and be sensitive to role of the family.

It is recommended that there is a review of the current supported-decision making processes around individuals who are at risk of institutionalisation and of the process by which decisions are made when people are ready to leave the institution.

2. INCREASE EFFICIENCY

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One of the advantages of the Beyond Limits Pilot is that it allows commissioners and providers the opportunity to reflect on the process of commissioning and tendering, and to explore the possibility that there might be other options.

The double dilemma for commissioners, using the current model of commissioning is that it involves at least two kinds of repetition:

- 1.** There is an initial professional assessment by the care coordinators, but this work is effectively repeated and done in greater detail by the service provider, who must design a detailed service design around the individual. It seems reasonable to wonder whether the role of the care coordinator could not be changed to play a more enabling role: checking the quality of service designs with critical questioning, limiting the duplication of assessment and planning by professionals.
- 2.** In developing a service design the service provider is working within a known envelope of resources and can work to achieve an agreed level of efficiencies. However opening up this process to competitive tendering, when other organisations will not have had the chance to work directly with the individual, seems unlikely to improve either the quality or the efficiency of the final service.

More generally there are questions about whether current tendering practices are always effective at supporting innovation and achieving the social and economic aspirations of a community in the round.[21] There is a danger that tendering regulations favour larger, international or existing services and are rather less well adapted to support small, local and innovative services.

Perhaps it would be possible to test out the development of this approach and to match people to service providers much earlier in the process. As long as people, and their representative, fully understands that they have a right to change their mind and to terminate their relationship with a particular provider (subject to any guardianship or other legal constraints) then it would seem more positive and efficient for all involved, to begin the relationship between the individual and the service provider at the earliest possible moment.

In addition, given the potential financial savings, and improved local economic investment of returning more people home more quickly it would seem possible to achieve the savings without open-ended bidding for work. Instead work could be distributed equitably between trusted service providers and within an overall financial settlement that would be beneficial to everyone.

Perhaps, working in this way, the whole process could also be speeded up. Given the commitment to return everyone (at least the current 43 people) home and the commitment to develop some other local providers, it would seem possible to be more intentional and inclusive in the strategy. While ensuring that Beyond Limits had sufficient business to survive and thrive, it would also be possible to identify some other local organisations who could start to provide services and who would then be mentored by Beyond Limits. This kind of strategy would speed up the process for everyone and would build confidence and competence more quickly and encourage good relationships.

Hospital resettlement processes in the past have often worked in this more intentional way. It seems unlikely that current commissioning practices cannot be developed in a way that would seem so beneficial to all concerned.[22]

It is recommended that NEW Devon CCG explores how best to develop its tendering systems, to try and identify other models that have been used elsewhere and to identify flexibilities within the current legal framework that could be used to develop a more efficient model.

3. STRENGTHEN STRATEGIC COMMISSIONING

The challenges of joint working between the NHS and local government have never been greater and it is encouraging that NEW Devon CCG, Plymouth City Council and Devon County Council do have a good track-record of joint work. It will be important to build on this past progress in the coming months and years.

Part of the challenge to joint working is that both organisations are often driven by central imperatives that are often in tension. In addition there have been radically different financial settlements for the NHS and for local government. Currently social care in England is facing an average cuts of about 33%.[23]

However, one of the most striking findings from our workshop on the Beyond Limits Pilot was that there were very real similarities between the goals of both the NHS and local government:

- ◆ Greater focus on individual and family control over services
- ◆ Greater personalisation of support, with more flexibility and less institutional provision
- ◆ Greater interest in growing local capacity and growing the social and economic capital of the local community

However, while the ultimate objectives seemed highly consistent and positive there was not always clarity about specific systems and plans. While the NHS in Plymouth had placed particular focus on the need to bring people back home and to develop new service provision, Plymouth City Council was transforming its whole system of social care.

Clearly there are risks for the future that must now be addressed:

- ◆ Messages to families and individuals about their rights and the responsibilities of local partners need to be clear.
- ◆ There needs to be a shared commitment to prevention and to early intervention (for children and adults).
- ◆ There needs to be a shared approach to developing the local capacity of support services and in the support offered by social workers, care coordinators and other professionals.
- ◆ There needs to be constant commitment to taking a shared approach to managing the financial risks associated with people with the most complex needs. Any breakdown in trust and joint working is likely to be expensive to both sides.

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A more joined up approach might bring significant benefits:

- ◆ Increased self-direction for citizens
- ◆ Greater innovation
- ◆ Provider development
- ◆ Investment in community

One of the opportunities for making effective use of diminishing resources would be to work more effectively at the boundary between health and social care, to develop more trust and to create more pragmatic joint arrangements.

It is recommended that more work is done to explore the integration of the NHS and local authority approaches to personalisation and, particularly, to identify the full range of out of city placements. It would be useful to know to what degree this is a shared problem and to what degree solving it could be a shared task.

CONCLUSION



The NHS in Plymouth is to be commended for beginning this project. The problem of crisis-driven institutionalisation is a national problem. While the Plymouth area of NEW Devon CCG already has lower rates of institutionalisation, the picture varies across the whole of Devon where rates are higher. The CCG does however have a clear strategic commitment to completely end this form of bad practice. If it is successful it will be a national leader and will rightly attract considerable praise and support for its work.

It is early days. A clear strategy is in place and action is underway. Early progress is encouraging. But there are also significant problems that need urgent attention.

The three major risks facing the project all have the same character:

1. The need to be decisive at the point people are ready to return home
2. The need to invest decisively in leaders and organisation
3. The need to build a shared strategic understanding

These are all leadership challenges that will require balancing the need to involve everyone to get shared understanding, with the need to act with clarity and determination.

Ultimately the ability to resolve this problem is partly about having faith in the strategy it has developed. The creation of the new Devon Clinical Commissioning Group, a clinically led organisation with the quality of care for its public and patients as its principle focus, is in a strong position to build on this earlier work. Its clear intention to foster collaboration and partnerships will be critical to its success.

Appendix - Research

This report is the first of three reports.

1. The first report describes the development of the pilot, its background, its objectives and outlines some of the challenges ahead.
2. The second report will explore some of the practical challenges, how they are being solved and any useful innovations that have been developed.
3. The third and final report will provide qualitative and quantitative accounts of the pilot's achievements of its own goals, detailing what has been learned and what more needs to be done.

36 Permission has been granted for all stories; however, to preserve anonymity all names and place names have been changed - with the exception of Winterbourne View. The crimes committed at Winterbourne View are a matter of public record and its closure has had an important impact on many individuals and families. Also, without referring to Winterbourne View it would be impossible to acknowledge one of the most striking findings of this report - **that Winterbourne View was considered to be one of the better institutions by families**. This fact does not prove that other places are even more abusive than Winterbourne View, but it certainly suggests we should be not be complacent.

1. QUESTIONNAIRES

People will be asked about how their experience of citizenship has changed - before and after the move. Where the person cannot communicate an appropriate representative will be identified.

QUESTIONS ABOUT CONTROL

1. Have you got a trust?
2. Have you got a bank account (sole or joint)?
3. Have you got a recorded way of sharing how you communicate with other people (if you do not use words)?
4. Do you make the important decisions about your life?
5. If not, who does?
6. Who is involved in recruiting your support team?
7. Altogether, how happy are you about how much you are in control of your life?

QUESTIONS ABOUT DIRECTION

1. Have you got a person-centered plan? (This is a plan that says what is important to you or what you want for the future?)
2. What do you want to change about your life?
 - ◆ Where you live?
 - ◆ Who you live with?
 - ◆ What you do?
 - ◆ Who supports you?
 - ◆ Anything else?
3. Are you learning anything new to make you:-
 - ◆ More Independent?
 - ◆ Need less help?
 - ◆ Get out more?
4. Altogether, how happy are you about your plans?

QUESTIONS ABOUT MONEY

1. Do staff support you where you live?
2. What things do they help you with?
3. Do you know what your support costs?
4. How much money do you get each week?
5. Where do you get your money from?
 - ◆ Wages for work
 - ◆ Benefits
6. Do you have a Direct Payment or an Personal Budget?
7. Altogether, how happy are you about how much money you have?

QUESTIONS ABOUT HOME

1. What kind of house do you live in?
 - ◆ Own your own home
 - ◆ Live in a council or housing association house
 - ◆ Rent your place from a private landlord
 - ◆ The family home
 - ◆ A registered home
 - ◆ A hospital unit or something like that
2. Who do you live with?
3. How many people do you live with (and is this your choice)?
4. Altogether, how happy are you about your home?

QUESTIONS ABOUT SUPPORT

1. Did you choose your own staff?
2. Do you get regular help from your family or friends? (Often – not just now and then).
3. Do you get help from other people in the community?
4. Do you have use of assistive technology to help you do things for yourself?
5. Do you administer your own medication?
6. Do you look after your money?
7. Altogether, how happy are you about how people help you?

QUESTIONS ABOUT COMMUNITY LIFE AND RELATIONSHIPS

1. Who is in your life and how often do you see them? (There is a special sheet for this question.)
2. What do you do in an ordinary week? (There is a special question for this question.)
3. Are you planning a holiday or a trip away?
4. Do you work?
5. Altogether, how happy are you about your relationships?

ADDITIONAL QUESTIONS

There are also some other questions that relate specifically to behaviour and which will be completed by an appropriate professional.

1. In the last year have there been any instances of restraint:
 - ◆ On how many occasions?
 - ◆ What was the nature of the restraint?
2. Is there a regular medication regimes - what was the medication dose and regularity?
3. PRN (as needed) medication:
 - ◆ How often was this medication administered?
 - ◆ What was the name of the medication and the dose given?
4. In the last year have there been any instances of 2:1 staffing
 - ◆ How often does this occur and for what reason?
 - ◆ Are larger ratios used at any time?
5. In the last year have there been any instances of Waking Night staffing
 - ◆ How often does this occur?
 - ◆ For what reason?
6. In the last year have there been any instances of Hospital Admission:
 - ◆ How many occasions?
 - ◆ How long was each admission?
7. Has he/she used any other services in the last year or longer?
 - ◆ What services have they accessed,
 - ◆ How long ago?
 - ◆ What was their involvement?
8. Any other information you feel would be helpful to know

QUESTIONS FOR FAMILIES

Families will also be asked about their experiences - before and after the move - with a particular focus on the following questions:

1. How often do you see your relative?
2. Has anything changed?
3. How are you kept informed of the welfare of your relative?
4. How would you describe communication between your family and the support provider caring for your relative?

5. How are you involved in planning for your relative?
6. How are you involved in important decisions about your relative's life?
7. How would you describe your relationship with your relative (in terms of ability to be with them, and them you, as much as you want)?

2. PARTICIPANTS

The names of families and individuals interviewed have been excluded. However the professionals involved in the workshops are listed below:

Naomi Chappell, Devon Clinical Commissioning Group
 Natasha Jackson, Student
 Ian Stevenson, Learning Disability Service, Plymouth Community Healthcare
 Kevin Treweeks, Housing Devon
 Tim Bott, Devon Clinical Commissioning Group
 Angela Martin, Havencare
 Claire Slade, Havencare
 Morna Boulbin, Michael Batt Foundation
 Pam Hemstead, Michael Batt Foundation
 Mike Goldsmith, Michael Batt Foundation
 Robin Vacquier, Michael Batt Foundation
 Sam Sly, Beyond Limits
 Caroline Debnam, Learning Disability Service, Plymouth Community Healthcare
 Liam Newton, Forensic Psychiatrist, Learning Disability Service, Plymouth Community Healthcare
 Soni Bhate, Psychiatry, Learning Disability Service, Plymouth Community Healthcare
 Doreen Kelly, Beyond Limits
 Gary Kent, New Key
 Jo Sly, Beyond Limits
 Chris Dorain, Plymouth City Council
 Paul O'Sullivan, Devon Clinical Commissioning Group
 Gavin Thistlethwaite, Devon Clinical Commissioning Group
 Fiona Phelps, Devon Clinical Commissioning Group
 Linda Newbould, Learning Disability Service, Plymouth Community Healthcare
 Lin Walton, Torbay Care Manager
 Carole Turnbull, Learning Disability Service, Plymouth Community Healthcare
 Kay Hughes, Clinical Psychologist, Learning Disability Service, Plymouth Community Healthcare
 Kevin Neal, Plymouth City Council, Adult Social Care
 Trevor Eardley, Independent Consultant
 Debbie Butcher, Plymouth City Council, Adult Social Care
 Fiona Gordon, Plymouth City Council, Adult Social Care

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Notes

- [1] More information on the research process can be found in the Appendix.
- [2] See Department of Health (2012a)
- [3] Some of the literature on institutionalisation is listed in the references and further reading section. There can be no assumption that institutions simply cause abuse, or that people will not be abused outside institutions, however there are very strong reasons and evidence to suggest that institutional provision tends to promote abusive behaviour. As Goffman, Wolfensberger and others have demonstrated, the structures of power, hierarchy and control associated with institutions tend to promote demeaning attitudes and to reduce people's natural resistance to act badly towards their fellow human beings. Institutions do not cause abuse, but they make abuse much more likely. It is this analysis which has been central to the imperative to close institutions and, in particular, the analysis of Professor Mansell, whose work on people with challenging behaviour has been central to government policy since 1993 (Department of Health, 2007).
- [4] See Duffy (2003)
- [5] See Care Quality Commission (2011)
- [6] See Alakeson and Duffy (2011)
- [7] It would be interesting to explore the gender balance in placements nationally. Although there are important gender differences in the prevalence of mental illness and some genetic conditions, these are unlikely to explain such an extreme discrepancy. One hypothesis might be that this discrepancy reflects the fact that the triggers for institutionalisation are acts of anger, violence and resistance and the fear that this generates in professionals and others.
- [8] We currently have no data for local authority or joint placements. The data above is for NHS placements only. It would be interesting to widen the data set for one of the future reports. This may improve our understanding of this shared problem.
- [9] In correspondence with the author, Dr Liam Newton made the following observation: "A number of clients placed out of area were placed in prison or hospital by the courts, sometimes against the wishes of local clinicians. This means that not everyone placed out of area is a result of commissioning

or a lack of local specialism. Although it is acknowledged that bringing people back might be due to some lack of local specialism. Linked to the above point it should be noted there are no secure learning disability beds in the south west; so if the courts decide that a person needs a secure bed they have to go out of area.” These are valid points and clearly they raise further important matters that need to be explored in developing the right set of local solutions.

[10] See Department of Health (2007)

[11] The history of these developments is described by Julia Fitzpatrick in the report, Personalised Support (2010). This whole section draws significantly on that report.

[12] See Fitzpatrick (2010)

[13] The original plan was developed as part of the NHS initiative known as QUIPP (Quality, Innovation, Productivity and Prevention). For more information on local implementation and the Beyond Limits Project see NEW Devon CCG (2010)

[14] For example, see Alakeson and Duffy (2011)

[15] See Fitzpatrick (2010) and Wands-Murray and Pearce (2012)

[16] See Cowen (2010)

[17] See Duffy (2010)

[18] See Duffy (2011)

[19] For example, see Broad (2012)

[20] In the current policy context the distinction between health and social care needs is also going to come under greater tension. It is arguable that the concepts were ever coherent and robust, but when funding for one area suddenly reduces relative to the other stability will be hard to maintain.

[21] See Yapp and Howells (2013)

[22] Yapp and Howells are currently developing a further discussion paper exploring more effective and creative approaches to commissioning within the current legal framework which The Centre for Welfare Reform will publish later in 2013.

[23] See Duffy (2013)

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