Getting There

LESSONS FROM DEVON & PLYMOUTH'S WORK TO RETURN PEOPLE HOME TO THEIR COMMUNITIES FROM INSTITUTIONAL PLACEMENTS

by **Simon Duffy**

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SUMMARY

NEW Devon CCG, working closely with local authority partners, have been leading a project of national importance to demonstrate that it is possible to return people with learning disabilities home from institutional placements and to end the practice of sending people away from Devon into such services. This project is called the Beyond Limits Project and involved developing a new service provider to offer people personalised support to ensure people came home to a safe, flexible and responsive service.

Since the project began 20 out of 51 people have returned home and a further 9 people have been stopped from leaving Devon and Plymouth, thanks to new commissioning and service provision arrangements and collaborative work by clinicians and community teams. This means that about £5 million is now being spent in Devon on local people and in the development of local capacity which would have been lost to the local health and social care economy. If the project continues to a successful conclusion then the remaining 31 people might also return along with the additional cost to the CCG of £5.3 million which is currently being spent.

The benefits of this new approach are multiple:

- People getting better lives, not living in institutional environments, but able to thrive and contribute to their families and the wider community.
- Development of competent support services that are able to work flexibly, adapt quickly and ensure the safety of people with the most complex needs.
- Development of closer working relationships between commissioners, health professionals and providers; breaking down barriers and embedding a 'can do' attitude and community-based culture
- Efficient and local investment of resources - improving the local community, its economy and its appreciation of the value and rights of people with complex needs.

Unsurprisingly the process of helping people to return home is not straightforward. There have been major challenges faced by people,

families and professionals. Yet these challenges are being addressed and NEW Devon CCG and its partners should be commended for its ground-breaking work in the three strategic areas:

Providing personalised support - All support should be personalised, but support for people with complex needs must be personalised if it is not to become abusive or breakdown. Commissioners recognised that this required investment in the kind of detailed planning and design work that must be led by service providers themselves. This has required a new approach to commissioning to involve the service provider earlier in the process of bespoke planning and design of services from the outset.

Responding to crises effectively - Problems and crises happen, but it is critical that people respond to these crises quickly and appropriately. Clinicians are often forced to place people in institutional services because of serious risks to people's safety and the involvement of the police. It is never a measure taken lightly and clinician's need to feel confident that appropriate community support is available. Today community teams and service providers are working more effectively to solve problems in their communities without resorting to institutional placements.

Reducing the risk of crises - The people who end up in crisis and who are then placed in institutional placements are usually known to services, but crises seem to accelerate when families are excluded from decision-making, when people are forced to accept local services which are not personalised and when organisational responsibilities are diffuse. There remain important challenges to ensure partnership between local government, schools and the criminal justice system.

It is heartening to see the level of commitment and intelligence being invested in NEW Devon there has been a real commitment to take this problem seriously and to innovate in order to solve it. This success has been achieved amidst the most difficult of circumstances, with radical structural change in the NHS and cuts in funding, particularly cuts that have been deepest in local government and housing.

The most recent national figures suggest that elsewhere in England the situation is getting worse, with more people being placed away from home, than there are people returning home. This is not the situation in Devon and Plymouth - where there has been significant positive progress. National policy-makers and local leaders should look to Devon and Plymouth for some important lessons on how to bring people home - for real - for Devon and Plymouth are getting there.

INTRODUCTION

This is the second of three reports commissioned by NEW Devon CCG to support the development of the Beyond Limits Project. The first report, Returning Home, described the reasons why people ended up in institutional placements and explored the logic of the local strategy - in particular the need to develop a new service provider with the skills, drive and experience necessary to provide new forms of support to people in the community (Duffy, 2013).

The final report will look at the **outcomes** of the project; but this second report is a chance for all those involved to reflect on the **processes** that are currently in place for managing crises, commissioning support and discharging people from institutional services. This report is not intended to be a comprehensive review or analysis of every aspect of the system. Instead it was developed to encourage conversations between key partners and to offer back some reflection on those conversations with some observations drawn from the previous experiences of resettlement, both in the UK and elsewhere. The aim is to offer a modest level of guidance to those already working hard to achieve the aims of the project, while also summarising the lessons being learned that might be useful nationally and locally.

The report begins by putting the work from Devon and Plymouth in its national context. Today there is a national drive to address the problem of excessive institutional placements for people with learning disabilities. Devon and Plymouth is making good progress, but most other parts of the country are not and the problems is actually growing overall.

The second section describes progress in the development of personalised support in Devon and Plymouth. The immediate challenge is to offer people the right kind of flexible support so they can return home successfully. Progress has been significant; it might even be accelerated further with some further improvements.

It might be useful to pay particular attention to:

- How to speed up the commissioning process for service delivery
- How to increase the supply of appropriate housing
- How to work more effectively with clinicians locally and in the placements

The third section outlines some of the work taking place to reduce the risk of new people being be sent away to institutional placements. There has been some very positive progress within clinical services, service provision and commissioning; this can be extended further across the whole of Devon and Plymouth.

In particular:

- Community teams can continue to support more local personalisation
- Multi-agency planning, including important partners like acute hospitals, the police and ambulance services
- Commissioners can continue to respond quickly to changing needs
- Service development and training can strengthen the capacity of everyone to respond to crises positively

The fourth section returns to some of the questions about the underlying causes which were raised in the first report. Here there are challenges which require new relationships with families, other public services and the criminal justice system.

Some of the themes that will need to be put at the heart of long-term strategic thinking:

- How to ensure effective advocacy for people with learning disabilities as they become adults and how the rights of families can be better respected
- How to work with partners in education and social care to help reduce other kinds of institutionalisation or the excessive use of out of area placements
- How to work with the criminal justice system to increase community safety and the excessive use of prisons for people with learning disabilities
- How to ensure sustainability of the approaches in the light of the Care Act, establishing sufficient community support and incorporating the role of the Safeguarding Boards.

The conclusion summarises some of the lessons for local and national agencies. In particular we return to the critical theme of this report - the need to take values seriously. It is easy to talk about recognising people's citizenship and the value of community life, but it's something else to **combine values with the kind of realism and pragmatism** that makes things happen. Communication and good ideas are important, but they must be followed by action.

Beyond Limits Project

The Beyond Limits Pilot began before the latest NHS restructure with an initiative in NHS Plymouth. It is an important initiative, not just because it aims to end the bad practice of unnecessary institutional placements, but also because it demonstrates how the NHS can work to develop a small local service.

The project's goals are:

- 20 people's lives will return from institutional services to have better lives - with more control, personal fulfilment, appropriate housing, good relationships and making a contribution to the community.
- A new independent service provider, based in Plymouth, available to provide support to people with complex needs, called Beyond Limits, developed in partnership with two expert professionals - Sam Sly and Doreen Kelly.
- In future nobody will be placed outside the city solely because their needs become complex.
- New models of support will be developed - support will be personalised and will focus on prevention, individual service design and supporting citizenship.
- New models of supported decision-making, where advocates, family or others are involved in representing and protecting the interests of people who lack capacity.
- 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.
- Better coordinated support and communication for families and individuals from both service providers and from the professionals from the multi-disciplinary team.
- Commissioning and funding systems will be more flexible, individualised and responsive
- Greater collaboration between health and social care systems and the further development of models of individual funding like personal health budgets
- The wider culture will have changed, in particular there will be greater belief in the capacities of individuals, families and communities
- 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

1. Background

It is worth remembering that the work described in this report, which aims to bring people home to Devon and Plymouth, began before the scandal of Winterbourne View raised the profile of this issue into a major political issue. In Plymouth the NHS had already begun to address the problems that were leading to out of area placements and service breakdowns, and it had already put in place a strategy to return people home.

However the Beyond Limits Project, and all the other associated work, is now inextricably entwined with broader national policy objectives. This both complicates and supports what the NEW Devon CCG and its commissioners are trying to achieve. It also provides local NHS services with an opportunity to share some of their findings about what it takes to get people home successfully and to reduce the pressure to send people out of the community unnecessarily.

For these reasons this report begins by setting out some of the key facts which explain why this project is important and the broader national context within which it sits.

1.1 Institutional placements

While England started to close institutions for people with learning disabilities earlier than most, this leadership came with a cost (Keilty and Woodley, 2013). Often the early alternatives were still very institutional: day centres and residential care services (often very large) were the norm (Duffy, 2013b). Community services were often inflexible and by placing people into pre-arranged groups it was often impossible to provide people with the personalised support that could keep them safe and well.

So, when long-stay institutions closed a fraction of the population were deemed too 'complex' for community life and were left in smaller NHS services, others were placed in a range of private hospitals or specialist units that sprang up as the old institutions were closed (Department of Health, 2007). It is interesting to note that there is nothing inevitable about this, the Scottish process of de-institutionalisation, which began more than 10 years later in than in England, avoided some of these errors and has seen more progress in the development of flexible community services (Fitzpatrick, 2010).

The price paid for this form of half-way de-institutionalisation has primarily been paid by people and families. Institutional services cannot, by their very nature, offer flexible support that connects people to communities or open up opportunities to a richer life. Instead they tend to constrain people and struggle to meet individual need. To the extent that institutional services close down opportunities for personal expression, freedom or love, they must also control the natural reactions to these missed opportunities. Hence patterns of abuse - direct or indirect - are almost inevitable. The scandal of Winterbourne View broke because Panorama put a camera inside it. There is no reason to think that Winterbourne View was unique - quite the opposite. In fact one mother whose daughter

had been in Winterbourne View said, the other services her daughter had experienced were "worse than Winterbourne View" (Duffy, 2013a, p.14).

The first report described how all six of those in the first group to move back home had been abused within the institutions (Duffy, 2013):

- 2 suffered neglect
- 6 had been sexually abused
- 5 had experienced physical abuse
- 1 had been financially abused

This local picture is also reinforced by the national statistics that are now being gathered in the wake of the Winterbourne View Scandal. The Health and Social Care information Centre now publish a Learning Disability Census in 2013, and it is expected that it will continue to do this until the problem of institutional placements is resolved (HSCIC, 2013).

These statistics come from that census:

- In the last 3 months **25.9%** of inpatients had harmed themselves
- **21.0%** of inpatients had suffered an accident in the last 3 months
- **22.2%** of people had suffered physical assault in the last 3 months
- Physical restraint had been used **34.2%** of people in the last 3 months
- **11.4%** had suffered seclusion in the last 3 months
- **56.6%** of people had been the subject of at least one incident involving self-harm, an accident, physical assault against them, hands-on restraint or seclusion during the last three months
- Antipsychotic medication used regularly or at least once in the last 28 days for **68.3%** of the people in the units

These are just statistics. But listening to people and families brings home the negative impact of this situation.

This testimony from one family member is typical:

> ***Professionals don't seem to understand what autism and Asperger's syndrome people need… his anger builds up with him. He's in an environment where it doesn't make sense - he's living in Bedlam. He's been forced to living in bigger and bigger environments which made him worse.***

A mother described how her daughter was "medically coshed" by the Assessment and Treatment Unit in which her daughter lived. To her the place where her daughter lived was merely "a holding bay - a prison." One lady's sister described the service as "worse than a prison. They can do what they want to and get away with it."

One father said:

> ***It is a prison - he's been institutionalised - I won't take my family, because he's changed so much.***

Families described the terrible toll this took on their family life. One family described how their son had been moved to place after place, each one breaking down. They now have to travel to Norwich from Plymouth - a round trip of **724 miles**.

1.2 A national problem

As the Learning Disability Census confirms, this is a national problem (HSCIC, 2013):

- There were **3,250** people with learning disabilities who were "inpatients with learning disabilities, autistic spectrum disorder or behaviour that challenges in NHS and independent services" at the time of the last census (HSCIC, 2013) in 104 provider organisations.
- 572 (**17.6%**) had been inpatients for more than 5 years and 1,949 (**60%**) had been inpatients for more than one year. However, as this data suggests there are still a considerable number of new admissions each year.
- Of these people 1,804 were in NHS services (**55.5%**), while 1,446 were in private hospitals or units (**44.5%**). Over half of these admissions had some 'forensic' aspect which means that they are associated with the criminal justice system in some way.

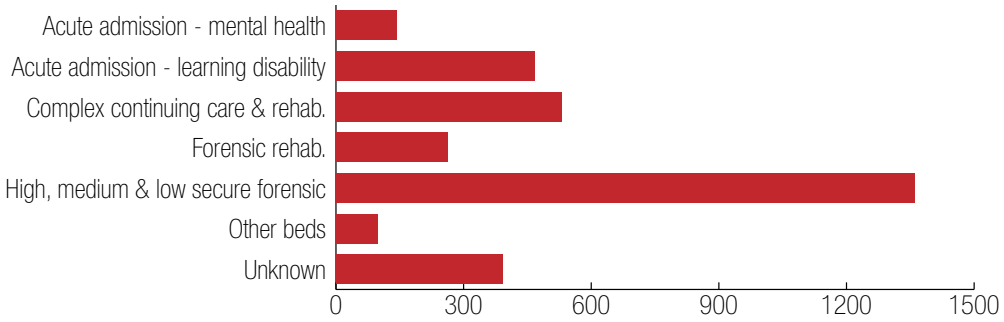

Figure 1 The kind of inpatient services people are placed in

The South West Region funds **152** people as inpatients of whom **80** are more than 100 km from their homes. **76** people were inpatients in local hospitals or units, of whom **12** are from more than 100 km from their home. As a region, the South West tends to send more people away from their homes than other regions.

Northern, Eastern and Western Devon CCG is the largest in the country (n=210) and it had, in September 2013, **43** people funded as 'inpatients' (1.3%) which makes it the 8th highest funder, and with **16** people living as inpatients **within the boundaries** of the CCG. [Note: these figures may include some people not funded by the CCG but by local government or another body.]

While the human cost is enormous, so is the financial cost. These services cost over **£0.5 billion** per year and the average cost per person is about **£172,000** per year.

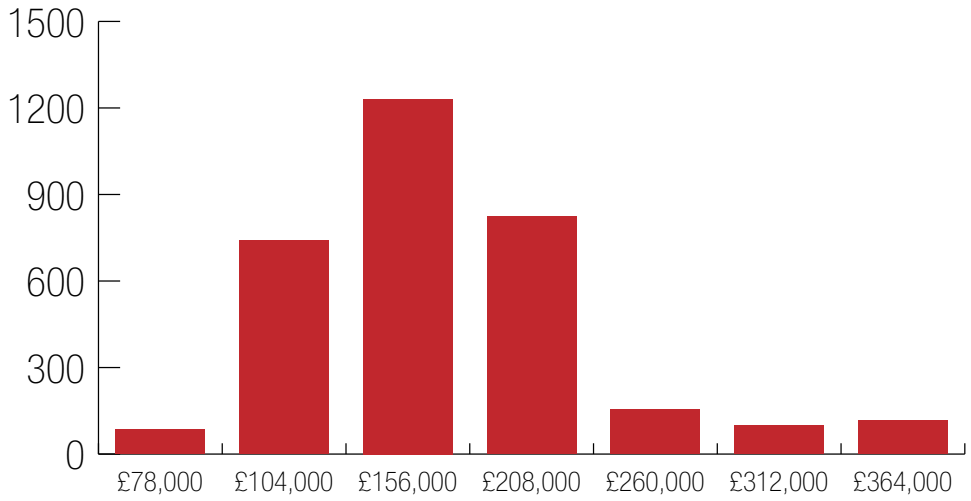

Figure 2 Spending on institutional placements

Yet the process of getting people out of these placements has been fraught with difficulties. Despite the fact that the *Winterbourne View Concordat* committed statutory services and others to find people appropriate community placements by 1st June 2014 the 2013 census found that **only 29.3%** of people had a plan for discharge. Moreover the most recent data suggests that the numbers of people placed as inpatients has even increased to **3,332** (NHS England, 2014).

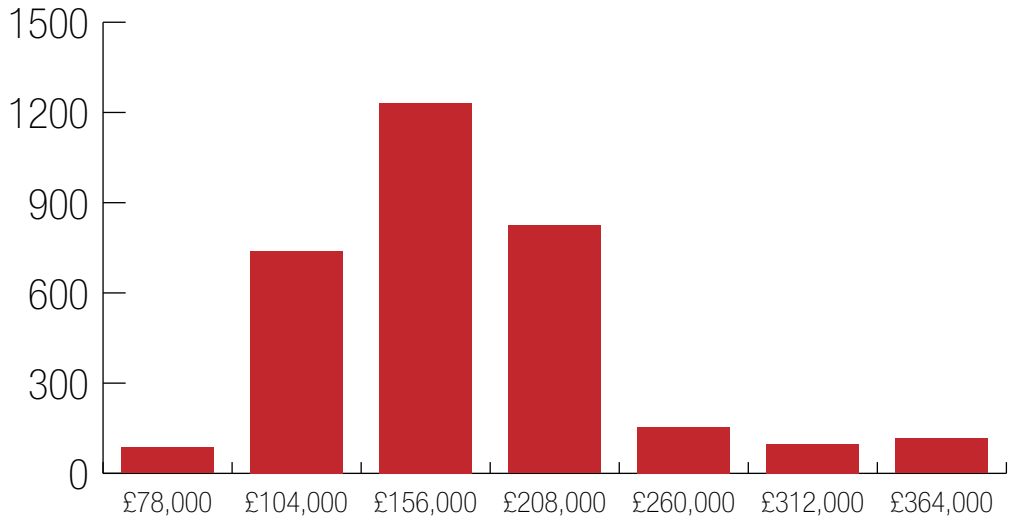

Figure 3 Length of stay in inpatient facilities

1.3 Local progress

Given the lack of progress nationally the positive progress in Devon and Plymouth is particularly encouraging. In May 2014 the CCG reported that there had been significant progress in helping people return home (see Table 1).

	Devon	Plymouth	TOTAL
Step 1 - initial review	4	1	5
Step 2 - service design	2	3	5
Step 3 - decision process defined	1	4	5
Step 4 - housing & support identified	2	0	2
Step 5 - team recruited	2	0	2
Step 6 - move	0	0	0
Step 7 - review	11	9	20
Appropriately placed	10	2	12
Total	32	19	51

Table 1 **Progress in helping people move back home**

Overall the figures show that of 51 people who were inpatients:

- **20** are now back home
- **19** are in the process of coming home, and
- **12** are deemed appropriately place

Given also that the Beyond Limits project began in Plymouth and this is where the early development work started it is perhaps not surprising that the number of people deemed 'appropriately placed' in inpatient care is much lower in Plymouth. It may well be that as the process develops further clinicians will start to have more confidence that competent and effective support can be provided locally.

In addition to this success is the equally important measures that have been taken to stop people from being placed in institutional services. Local commissioners have identified that at least **12 people** have escaped such measures by the combined work of commissioners, clinicians and service providers.

This means that 20 people have returned home and 12 people have been stopped from leaving Devon and Plymouth thanks to new commissioning arrangements. This means that about **£5 million** is now being spent in Devon on local people, in the development of local capacity, which could have been spent elsewhere on institutional services. If the remaining 31 people were also returned then an additional **£5.3 million** which is currently being spent outside NEW Devon or on institutional services within NEW Devon would begin to be invested in community services.

2. Commissioning

To provide support to people with the most complex needs requires the most personalised support. Unfortunately the common response to complex needs is to provide increasingly institutional support, which in turn can often lead to learned negative behaviours, emotional breakdowns or mental health problems. Put simply, we often respond to people's complex needs with highly inflexible and institutional services, which then makes their problems worse. Often such services, while they may aim at assessment, treatment or some therapeutic response, become places of containment.

In *There Is An Alternative* some of the organisations who have been most successful at supporting people with complex needs summarised the key elements necessary for getting people home successfully (ASL, 2011):

1. **Person centred** - positive listening to actions and behaviours
2. **Cooperation** - working with the person and their family for success
3. **Investment in skill** - ensuring supporters have the right skills and support
4. **Leadership** - personal commitment and presence from management
5. **Sustained effort** - commitment to work through problems and not give up
6. **Local back up** - expert clinical services, present in the local community
7. **Will** - the commitment of local commissioners to local community services

This analysis mirrors the kind of thinking that was set out by Professor Jim Mansell, who was the leading academic studying responses to challenging behaviour.

In his report for the Department of Health he described the fundamental problem (DH, 2007):

> ***…commissioning has been too reactive and has therefore become dominated by trying to manage crises.***

The problem then is not that we do not know how to support people with complex needs in the community, rather it is that the will to do so is missing. Instead commissioners are often forced to react to crises by agreeing to fund placements elsewhere. Building the capacity to support people locally or working out how to avoid such problems in the first place has often not had the priority it should.

It may not be an accident that this problem has grown alongside the development of the 'purchaser-provider' split. Nationally the relationship between commissioners and service providers can be fraught with tension and problems of trust. For example, in the implementation of personalisation there has been a very low uptake of options which

enable much greater service provider flexibility (ADASS, 2014). The fact the Beyond Limits Project tackles this problem so directly is one reason why it is such an exciting national development.

For here, in Devon and Plymouth an intentional commitment to develop new forms of provision, to work in partnership with the local services and to even create new organisations, has begun to generate the kind of trust and mutual commitment that is essential to solving the problem of institutional placements.

Here are just a few of the comments that local professionals and families made about what they were seeing:

- Real quality of life improvements
- Planning is very person centred
- Great teams being developed around the person
- Families really feeling supported
- Institutions being challenged
- Growing confidence in support arrangements

As the numbers suggest, and as these comments reinforce, NEW Devon CCG seem to be making a real success of the resettlement process. The questions that then arise are primarily about refining and building upon this success.

2.1 Leadership first

In practice the paradox at the heart of an effective resettlement process is that success for the person depends upon the development of thoughtful and highly personalised support, while success for the system depends upon being well-organised, driven and efficient.

Successful resettlement manages to pay attention to both imperatives:

1. To design and deliver effective support in partnership with people and families
2. To quickly and efficiently move people out of institutional care back to their own homes

Putting too much emphasis on the former, at the expense of the latter, often leads to far too many people languishing in environments where at best positive development is unlikely, but at worse people are subject to abuse. Putting too much emphasis on the latter means that people leave institutions quickly, but are not supported correctly and quickly support unravels, people become unsafe and new crises arise.

This does not mean compromising - it means ensuring that the resettlement process is both person-centred **and** well organised and efficient. This means bring together person centred thinking with system thinking (Duffy, 2004).

Getting someone with complex needs, which often include behavioural problems, back - safely - into their own community is complex. It is quite possible, but it requires attention to detail at every stage: assessment, service design, service development and on-going support (Fitzpatrick, 2010). To make this process effective demands clear and consistent leadership, as early as possible in the process.

Unfortunately the services system, across England, has found it difficult to deliver the right kind of leadership. People with complex needs often find themselves crossing

organisational boundaries (education, health and social care) and often professional responsibility is confused (clinical, nursing, social work etc.)

As one family member put it:

> *In the past there was nobody whose job it was to help bring them home - I've never felt confident. Instead health, education, social services seemed to just be fighting about funding with each other.*

Talking with families who were in the middle of the process, there were clearly some positive changes that they had identified (although balanced by some understandable caution). Each family was clear that it was the job of Beyond Limits to get their family member out of the institution and they could name precisely who in Beyond Limits they saw as responsible for this. Crucially families were encouraged by the capacity of Beyond Limits to take practical and progressive steps.

For example, one family said:

> *It's amazing that staff are being recruited in advance.*

Another was impressed by their ability to craft the support team:

> *We are involved in picking the staff. It was a wonderful experience - because of course we know who will be a match.*

In fact families themselves can become central to the whole process of building the team around the person and help find appropriate supporters from within their extended networks. There is no doubt at all, for most clinicians, that this process of team matching was the "cornerstone of success."

However some clinicians also noted that this development process, if it was undermined by undue delays, could somewhat unravel. Teams can be recruited, but if people do not move into their new home in a timely fashion then these teams cannot be sustained. Maintaining a reasonable pace is essential. This touches on one of the most important general issues that underpinned almost all conversations - the need to find the right pace and structure for the process.

In this regard it does seem possible to perhaps develop the current model of commissioning somewhat further. When commissioners know, as they do in these circumstances, that there is only a limited supply of service providers with the necessary capacity to help someone return home safely, then the priority must be to make efficient use of that limited capacity and seek to grow the capacity of the sector further within their local area. This means identifying the appropriate providers and then linking the right leader and organisation to the person in most urgent need of discharge - with a focus on reducing obstacles to discharge. **This would be more effective and efficient than forcing people, families or organisations through a process of 'tendering and procurement.'**

Much time would have been saved locally if the process for assigning Beyond Limits or other providers to individuals had been speeded up. National policy leaders should learn this lesson and begin to focus on the best use and development of existing capacity or growing appropriate new service providers who have the values and skills to create highly flexible and individualised support. Old style systems of procurement are liable to both redundant and harmful (Howells and Yapp, 2013).

2.2 Housing

An obvious element of any support package necessary to get someone back home - is a home. However this was a common cause of concern for everyone involved in the process.

As one commissioner wrote:

> *Lack of suitable housing creates a problem; this is also exacerbated by the limits on housing benefit. The personal budget may have to compensate for the additional rent because most accommodation classed as social housing is not always appropriate for the people we seek to support. We also have to consider neighbours and other environmental factors in placing people in the community.*

Another professional put the matter bluntly:

> *People are stuck because of a lack of a home*

There has been a tendency to think in terms of 'specialist housing' as if there is some special kind of housing that is most appropriate for people with complex needs - but this is the wrong way to think.

The right housing is housing that is right for a specific individual:

- The right **location**, close to important people (or perhaps away from certain people)
- The right **design**, respecting needs created by any physical or sensory impairments
- The right amount of **space**, appropriate for the support around the person
- The right **safety features**, alarms, sound insulation or other features that reduce the risk of harm to the person or those around them, including neighbours

Finding the right house and having the funds necessary to rent, buy or adapt it is an essential speciality skill for a resettlement process of this kind.

Ideally commissioners should be able to:

- Draw on the expertise of national agencies like the Housing and Support Alliance who provide advice on funding models
- Ensure access to social housing is available by building partnerships with housing and ensuring that more efficient pathways are developed to access housing
- Using budgets to subsidise rent or capital directly - housing costs are always a small percentage of the long-term costs of a package and getting the right house quickly is more efficient than putting people in the wrong location or allowing long delays
- Being open to use the private sector - remembering that the vast majority of housing in the UK is in private hands but may be available to purchase or rent
- Maximising housing benefit levels - most people need bespoke properties that will fall well outside the benefit funded range.

Participants were clear, for instance, that support from Plymouth's own housing department has been excellent. However, while people could be prioritised for council housing, this housing was often not appropriate; perhaps because of issues of noise, neighbour or space. This has made it necessary to use more bespoke housing solutions like shared ownership.

In reality the need for urgency, the relatively small numbers of people involved and the individuality of each person's needs means that the strategy needs to be driven, pragmatic and opportunity-focused. This will require personal leadership within the system and the access to the right kind of expertise to solve problems as they are identified.

One further problem faced by the project has been the Ministry of Justice's requirement that there be a fixed address for a person before any leave of absence can even be planned. This commits individuals and providers and commissioners to investing in a house before there is any proper understanding of the individual's need has been explored or tested in the community. It also creates additional costs for commissioners, to secure a home merely for the purposes of arranging such leave and prior to any actual agreement for discharge. The current model seems to imply that people will be discharged into institutional care services such as a residential home (where the living arrangements are less fixed and more easily changed). This problem highlights the fact that traditional assumptions about individuals and their care arrangements need to be challenged in the wider system in order to enable sustainable solutions for life in the community.

2.3 Clinical decision-making

There was a strong sense from families and clinicians alike that the services within which people are placed do serve to slow down the process of discharge, in a way that was not in the person's best interests. Cynically it could be argued that this is because the existing provider has a financial incentive to maintain the person in the service. However this may not be the main reason.

At one level there is simply a profound culture clash between those on the one hand whose business is to support people in the community and who believe that this is likely to be best for people, while on the other hand an institutional service whose rationale is about keeping people safe and away from harm.

As one professional put it:

> *There is still a massive gap and lack of understanding between the hospital medical model and our model meaning the hospitals cannot comprehend people surviving without locked doors and restraint etc.*

For some this problem was linked to the need to explore hypotheses about the reasons for people's behaviour or the conditions under which it might change. However institutions are highly risk averse and they tend to block any possibility of testing out 'what if…' scenarios. This then adds to the overall level of fear and anxiety associated with the individual as no new data can be gathered.

Another reason may be the nature of the legislation which surrounds much of the service provision. Table 2 below sets out the national data describing the legislation framing most (but not all) placements.

As one family member put it:

> *It's like a quagmire, once you're sectioned with a learning disability you can never get off.*

Not subject to the Mental Health Act 1983 (informal)	718
Formally detained under Mental Health Act Section 2	323
Formally detained under Mental Health Act Section 3	1100
Formally detained under Mental Health Act Section 35	33
Formally detained under Mental Health Act Section 36	6
Formally detained under Mental Health Act Section 37	288
Formally detained under Mental Health Act Section 37 with section 41 restrictions	405
Formally detained under Mental Health Act Section 44	0
Formally detained under Mental Health Act Section 45A	4
Formally detained under Mental Health Act Section 47	25
Formally detained under Mental Health Act Section 47 with Section 49 restrictions	129
Formally detained under Mental Health Act Section 48	3
Formally detained under Mental Health Act Section 48 with Section 49 restrictions	39
Formally detained under Criminal Procedure (Insanity) Act 1964 as amended by the Criminal Procedures (Insanity and Unfitness to Plead) Act 1991	23
Formally detained under Mental Health Act Section 135	1
Formally detained under Mental Health Act Section 136	0
Formally detained under Mental Health Act Section 5(2)	27
Formally detained under Mental Health Act Section 5(4)	3
Formally detained under Mental Health Act Section 4	3
Subject to guardianship under Mental Health Act Section 37	10
Subject to guardianship under Mental Health Act Section 7	1
Formally detained under other acts	22
TOTAL	3228

Table 2 Legislation framing discharge process

Another family member said:

> *Once she was sectioned - I was in limbo land - it became nobody's responsibility - only the last year or so have - I learned about the commissioners and the system - only just learned from Sue and Sam about complaints.*

Another noted that the turnover of staff was also a problem:

> *He's had 7 doctors since he's been there - it will be a very brave man who will sign him off.*

These problems also interconnect with the problem of getting the right kind of housing, as one professional described:

> *Delays in the Court of Protection decision making process for people requiring tenancies who lack capacity. This can currently take six months. We envisage this will become a worsening situation following the impact of the Cheshire West ruling.*

However discussing this matter with leading clinicians there was a strongly held view that any block was not created by the Mental Health Act itself. Rather it was a breakdown in leadership and communication. Within the hospital (or similar service) there would always be a Responsible Clinician (RC) who would be accountable for any discharge. It was vital that the RC was acknowledged and, ideally, local clinical leaders should be the ones to communicate with the RC.

As one doctor put it:

Doctors always respond well to doctors

In fact clinicians tended to feel that the Mental Health Act could rather be an aid to effective discharge, ensuring as it did regular scrutiny and review of the case, ability to have a second opinion from another doctor. What remained unclear was whether it might not be possible for people who are 'under a section' to be supported or treated in their own home. Or alternatively can the necessary securities and mechanisms put in place so that someone can be safely supported at home without having to the 'under a section'.

This area seems to require some greater clarity, not just for the sake of clinicians and service providers, but also for people and families who are often left bemused by legislation - which aims to help - but can feel like a damaging hindrance. There is an awareness of risk and the potential for personal accountability, but actually where this risk really lies is unclear. It was also unclear whether people fully understood the nature of the risk that the service provider too. There was perhaps insufficient consideration of the service provider's duty of care and the accountability this created.

Also, as Figure 1 indicated, more than half of these services are 'forensic', which means that there is likely to be involvement with the criminal justice system and a range of further complexities and bureaucratic procedures. Again, this means that clarity of leadership and personal responsibility is at a premium, unnecessary delays or uncertainties about commissioning are toxic to effective resettlement.

2.4 Maintaining the right pace

The process in Devon and Plymouth are working. There is a clear - 7 Step Model (see box) and several of those involved expressed great relief that there was a clear process which allowed mapping, progress chasing and had a clear logic:

It's great to have a model that is clearly expressed and understood

But this process could still work better. As one family said:

The process is too long - there's no need for it to take 2 years.

The delays in the process do not come from personalised support itself. It does not take a long time to create an individual service design (a plan for the service, including housing and support arrangements) nor does it take long to develop a working policy (a detailed description of how to support the person successfully). Most of the essential work can be carried out in 2 full days of planning - if the necessary people are involved.

7 Step Model

1. Identification and review
2. Individual Service Design
3. Decision-making plans
4. Support & housing identified
5. Team recruitment
6. Move
7. Monitoring and support

Without a doubt the key issue locally and nationally is how to maintain a good pace for the resettlement process. The process certainly has a maximum speed - which should be defined by the capacity of service providers to develop the necessary alternative support systems - this can take a few months.

However the speed is much lower when:

- There are confusions and delays in getting clinicians to agree to discharge
- Suitable housing is not available
- The local community team is not ready or confident
- There are capacity problems within local teams and commissioning slows the process down - for this work is just one of a number of competing initiatives that place demands on local services

There can be no artificial solution for these problems, they are real and they need to be worked through. Ideally commissioners will work with clinicians, service providers, community teams and housing experts to be ensure that - for each person - **personal responsibility is crystal clear**.

Commissioners in NEW Devon CCG have already demonstrated that a creative and pro-active approach to commissioning service provision is both possible and effective. It would be useful to go further and to speed up the final stage of resettlement by a more direct approach to assigning service providers to individuals at the earliest possible moment.

3. Resolving crisis

As we have seen, institutional placements are not made lightly. Clinicians and Learning Disability Teams do all they can to keep people safe and remaining at home. However, when problems arise, if they don't feel that local services have the capacity to respond appropriately then they are inevitably drawn to look for more extreme solutions.

Even before the Beyond Limits Project there had been significant efforts by the Learning Disability Teams to address this issue by trying to offer support or commission new individual support arrangements. However there seems no doubt that the project has raised the bar. The project has demonstrated that new levels of flexibility and responsiveness can be expected from services. There have been no out of area institutional placements in Plymouth in the last two years.

As one professional noted:

> *The community team in Plymouth are now thinking in more positive ways about people returning and using much more positive language about keeping people out of hospital. They should be proud.*

One development which underpins this success has been the **Blue Light Protocol** which sets ground rules for how crises should be dealt with (see Box).

At the heart of this process is good communication and personal responsibility:

> *This has saved us at least £750k and nine out of area placements. Clinicians and staff report feeling supported by commissioners during a crisis when this has been used. [Toker-Lester, 2014]*

The Blue Light Protocol underlines the ongoing importance to review:

1. **Provider capacity** - Current support providers have the skills and practical capacities necessary to meet people's needs in the community. There is clearly growing confidence that this is possible, but it is still a process in development. There need to be at least a handful of organisations alongside Beyond Limits to whom commissioners and clinicians can look with confidence when supporting people with the most complex needs.
2. **Skill development** - Both service providers, community teams and clinicians need to be mindful of the need to maintain a level of skill and competence in diagnosis, behaviour analysis, communication, individual service design and positive behavioural support. There was clearly concern that this process was not necessarily being underpinned by the current academic system. For example, according to one participant, there will be a drop of 50% of learning disability nurses over the next three years.

Blue Light Protocol

As part of the aspiration to keep people cared for in their own home or as close to home as possible, it is necessary to avert crises and support each other across services to deliver our aim. It is written into the NEW Devon CCG contract with Devon Partnership Trust that no placement should take place out of area without the agreement of the commissioner.

Crises should be avoided by effective planning for a person with good contingency arrangements in place, but occasionally there are times when a multi-disciplinary discussion, usually by conference call at short notice, in order to help solve problems is useful. This protocol describes when this 'Blue Light' response is needed. Who should attend and what discussions should take place.

This process is instigated by a senior manager within the provider service (DPT) when an individual has been identified who is at risk of being placed out of area, or is at risk of losing their home, due to an unmet clinical or social need creating crisis. The senior manager within the provider organisation will usually have been alerted to the need through a member of staff within the service who is managing the care of an individual in crisis. The list of invitees could include the following people, but this is not prescriptive:

- **Psychiatrist** - to provide feedback on assessed needs and risks and if necessary play their role in the Mental Health Act process
- **Named Nurse** - care management and coordinating role, provider of clinical information
- **Social worker** - care manager, involvement in assessment and care planning
- **Modern Matron** - to provide expertise and support
- **IMHA/IMCA** - As required
- **Commissioner** - To provide support to fund alternatives to institutional care
- **GP** - To ensure effective support around health needs as required
- **Advocate** - As required to support the individual

The protocol goes on to give precise descriptions of how to set up the necessary conference call, to protect the necessary time and record discussion and decisions. The order of preference for support arrangements is as follows:

1. Support the person at home with the relevant help taking place there. Additional support packages will be considered favourably by commissioners.
2. The person is supported in a local non inpatient unit, using residential nursing, or short breaks services.
3. A local inpatient service in the NEW Devon area - Please note that Mental health needs should be met in acute mental health services and underlying physical health needs in acute hospitals - Inpatient LD units should not be inappropriately used.

Finally, out of area placements should be avoided at all costs. If an out of area placement is suggested it needs to be approved by the commissioner in line with the contracting process, and would only ever be considered when the move is clinically justified and all other avenues have been exhausted. Any gaps in local delivery should be reported to the relevant commissioner if needs cannot be met locally.

3. **New skills** - Further to this several professionals noted that some of the demands of this new way of working - focused on citizenship, community, ordinary housing and personalised support - created very different training needs. Training was often too silo-based, focusing only on a professional group. There was often a failure to include the wider knowledge of entitlements and community options necessary today.
4. **Local beds** - Being able to provide some local inpatient facilities certainly seems preferable to allowing people to leave the area. However there is uncertainty about what the real need for beds amounts to. If people have been going into inpatient facilities largely for lack of good local services then it is not clear what level of inpatient provision is necessary - if any. This was naturally an issue that concerned local clinician's significantly.

One of the ideas that was being explored in these discussions was the idea of a local concordat - a way of bringing together the diverse and groups working in this field to explore what each can do to support the development of a stronger and more sustainable system.

Redefining relationships between providers

Helen Toker-Lester reflects on the need for partnership between different service providers:

Once a person has returned to the community there is still a large amount of learning for everyone involved that is required to sustain a person at home. The new experiences of community living, and the stresses of everyday living can be difficult for individuals. Additionally any underlying mental health needs may require some ongoing support from clinical services.

For one person we support and on one occasion, things became too difficult for the person this meant using a local in-patient unit. Given the values of the project there was a need to redefine the relationship with the inpatient unit that reduced the risk of relapsing into an over reliance on clinical care in an inpatient setting. A scenario that was a frequently reported phenomena prior to Winterbourne view. The admission into the inpatient service created a need to ensure that the working policy for the person was shared with in-patient staff, and the clinical provider enabled staff from the community team to work into the ward. The provider (Modus) understood the need for tailored responses and had redesigned their hospital unit into individual accommodation with teams around each person.

As a consequence the working policy was examined with shared learning across the two organisations for the benefit of the person. The use of the inpatient unit was planned to be short, a matter of weeks, enabling the person to return home safely. The same provider also enabled another person to transfer from secure hospital care to their local unit as a 'stepping stone' to community living, enabling Beyond Limits staff to work with them to get to know the person. There is a danger that past experiences of clinical services, and particularly inpatient care has potentially demonised those services and therefore this renders them "untouchable" within the new paradigm of person centred working. However, as in the rest of our population, rarely, people do sometimes need care from clinicians in a hospital unit. The key is redefining that inpatient intervention as brief and purposeful, one that includes community staff, families and advocates in the planning of care, and an intervention that creates learning and adds value to the commencement of life at home as soon as possible.

4. Avoiding crisis

As the programme in Devon has worked with more people to help get them home a consistent pattern emerges from the data:

- 15 out of 16 been involved with services since a child - 94%
- 10 out of 16 have experienced forms of abuse in the past - 63%
- 14 out of 16 been detained under the Mental Health Act - 88%
- Each person has lived in an average of 10 institutions so far. The person with the fewest admissions is 4, the most is 25.
- 6 out of 16 have been involved in the criminal justice system - 38%
- 9 out of 16 have lived in residential schools - 56%
- 7 out of 16 have lived in residential colleges - 44%
- 15 out of 16 have lived in residential homes - 94%
- 5 out of 16 have had long admissions to acute hospital - 31%
- 14 out of 16 have lived in semi-secure or secure Specialist hospitals - 88%
- People were on average admitted to an institution for the first time aged 14 with the youngest being aged 2 and the oldest being aged 23.

While every person is different this data, and the stories and the data from Returning Home (Duffy, 2013) reinforce a picture which suggests that a crisis within a family often leads to a young person being institutionalised. The young person's negative reactions to that institutional environment then seem to lead to an escalating crisis where the first service is replaced with an increasingly institutional alternative (see Figure 4).

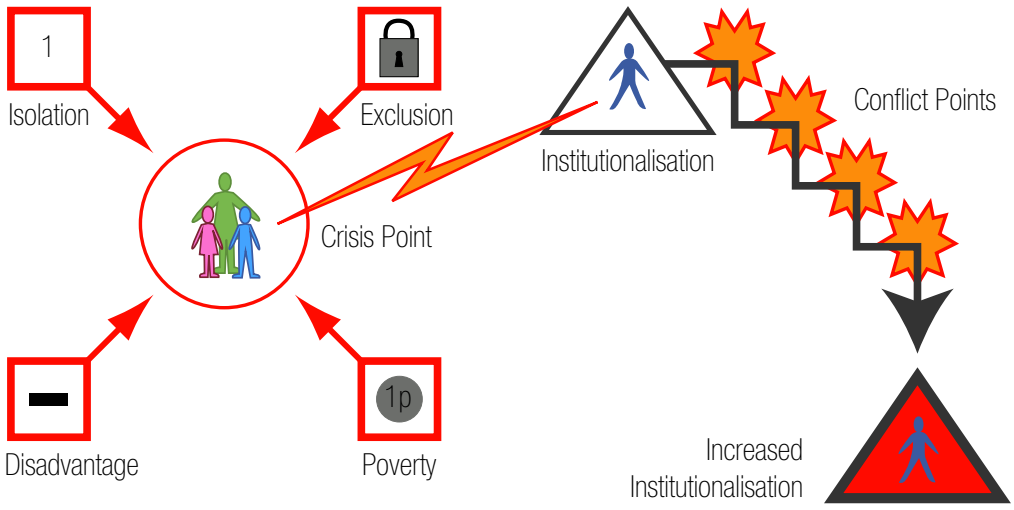

Figure 4 How people end up in institutional placements

All of this implies that preventing crises in the future will require some very different thinking and practice in a number of different areas:

4.1 Criminal justice

It was noticeable that one of the organisations that was not a signatory to the *Winterbourne View Concordat* was the Ministry of Justice.

This was an issue raised by several participants at events and reflects some stark realities:

- More than half of the institutional placements are in services forensic
- Police involvement can seem 'clunky and communication poor' in some cases
- Neighbourhood complaints often create a "tsunami" of pressure on commissioners
- There are approximately **20,000** people with learning disabilities in prison, that's **25%** of the prison population (DH, 2009)
- **72%** of male and **70%** of female sentenced prisoners suffer from two or more mental health disorders. (DH, 2009)
- Hate crime against people with learning disabilities is a significant problem (Sheikh et al. 2010)
- Police services are only just beginning to think about how to respond better to people with learning disabilities (Henderson & Feather, 2013)

For this reason it is encouraging to see progress in working with the police. The work of Henderson and Feather to support Devon & Cornwall Police and how they can work more effectively with people with learning disabilities is important. The development of 'police passports' may prove a useful initiative. There is also an Diversion from Custody project which uses NHS funding to ensure there is access to appropriate support inside police stations.

But this whole area is underdeveloped and the NHS will need to work closely with police and local government if it is to understand how so many people with learning disabilities become both victims of crime (including institutionalised abuse) and how so many are also caught up within the criminal justice system. This issue needs to remain a top priority for local leaders.

4.2 Local government

Although local government and Directors of Adult Social Services have the critical leadership responsibility for people with learning disabilities it is perhaps not surprising that leadership on resettlement has largely been based in the NHS.

- The NHS locally and regionally commissions the majority of the inpatient services that have come under recent scrutiny.
- Local government has been subject to severe cuts and is having to work hard to both sustain and redesign existing social care services.
- The incentives are unclear as regional NHS funding does not see ring-fenced and so savings created by reduced institutionalisation do not necessarily benefit local services.
- Often the actual trigger which leads to institutionalisation takes place well before someone is an adult (e.g. 56% of those working with Beyond Limits had been at a residential school).

Yet there are many good reasons why local government and the NHS should work together, not least because of the joint funding ('Better Care Fund') which central government is using to encourage more integration.

Perhaps most importantly institutionalisation and the unnecessary 'export' of local citizens outside Devon and Plymouth is not limited to NHS funded services. Both children and adults continue to be placed outside the local area into residential services.

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. Nationally, the National Mental Health Development Unit (NMHDU) estimated that out of area placements for mental health cost £690 million per annum, therefore the combined cost of out of are placements is likely to be more than twice that amount, that is over £1.5 billion (NMHDU, 2011). This implies that, even if there is a significant overlap between the 3,300 people in inpatient care and the 11,000 people with learning disabilities in out of area residential care placements, more than 9,000 people with learning disabilities are placed out of area in other kinds of residential care settings. And while the per capita cost may not reach the extremes of inpatient care it is also likely to be a very significant sum.

Moreover the factors that lead to crisis and institutionalisation - even when the NHS does end up funding the cost of inpatient care - are very likely to be significantly influenced by local authority services:

- Availability of suitable social care support
- Placement practice in children and adult services
- Practice in special education
- Level of early intervention (or the lack thereof caused by high eligibility criteria)
- Safeguarding procedures
- Social work practice
- Local voluntary and advocacy structures
- Transition arrangements for school leavers
- Inclusive education available
- Family support available

Almost all the significant factors that will ultimately drive demand for inpatient care are either directly or indirectly under the influence of local government or the NHS. It is impossible to imagine that long term success will not depend on the strongest possible joint working between health and local government in Devon and Plymouth. As it currently stands this would seem to be a priority for action.

4.4 Families and advocacy

One further issue which is of critical importance is the way in which the system can learn to work more effectively with families. If there was one consistently striking finding from the first report it was that the real point of crisis often came when the young person became technically an adult (Duffy, 2013a). We do not have enough information to confirm this, but it certainly seems highly likely that for people with learning disabilities, when they become an adult the system frequently does not know how or when to respect the role of families as their representative.

This is a complex issue, because mental capacity is a complex concept and simplistic solutions to mental capacity often cause significant problems. But if someone who is not capable of making all their own decisions, or who at least needs consistent and loving advice, is suddenly treated as if they can make their own decisions then this may cause harm.

Even the existing representational and advocacy arrangements - for example, the use of Independent Mental Capacity Advocates (IMCA) - may be too limited and bureaucratic to really resolve the most complex difficulties.

This is a profound issue, because it gets to the heart of people's rights and their ability to act as a free citizen. If the support arrangements from family or professional are inadequate — or if they are inadequately respected by others - there will be a crisis of decision-making. This could easily become the critical trigger that leads to problems escalating. Leadership and decision-making is always critical, not because people shouldn't be allowed to make mistakes - but without clear leadership nobody can learn and act upon their mistakes.

4.5 Lesson for commissioning

The Beyond Limits project is a great example of excellence in commissioning. But is also demonstrates that excellence here is driven by a commitment to values, partnership working and respecting the expertise of others. It is precisely because commissioners know their limits that they are being effective.

The task of resettling the remaining people placed outside Devon and Plymouth could be complete in a year or so. This will be a great success.

However the real success would be to take the lessons learned and apply them more widely:

- To understand when and how power and control can properly delegated to individuals or families
- To work with service providers respectfully, encouraging innovation and leadership, cutting down bureaucracy
- Building the kind of local partnerships which will ensure Devon and Plymouth can become more resilient communities where people with learning disabilities are not institutionalised, but are welcomed, included and enabled to contribute.

CONCLUSION

Significant progress has been made in getting people home and in providing positive support to keep people safe in their own communities.

The overall culture in the current system is beginning to change. There is greater resistance to people leaving their own communities and higher expectations about what people can do and what organisations can do to support them.

Beyond Limits has done good work which is highly respected. Families value their commitment and there have been some early success stories, albeit there is still much to learn and the risks around people remain very real.

There is a growing sense of partnership between clinicians, members of the community teams and the service provider. It would be good to build on this, to ensure that the best possible use was being made of each other's skills and to create stronger partnerships with universal services (e.g primary care, housing, police etc.).

It is time to review some of the processes around service development and discharge from hospital. The overall process could be both more efficient and speedy if there were some changes in how this process were managed. e.g. clinicians need to be empowered to lead negotiations with the current service provider and 'responsible clinician'.

It is time to build on this early small scale success and to ensure the lessons are learned in order to promote:

1. New forms of commissioning to support and foster community responses
2. New support and service models that can help people sustain their place in the community
3. The focus of energy and talent in community teams
4. Ensuring there is broad strategic agreement, with clinical leaders at the heart of strategy

It is time to draw some of these successes and the wider problems to the attention of central government. If they are wise national policy-makers will learn the lesson that they can only expect to see real change if they put in place the necessary leadership alongside people and families that can actually design and implement the necessary support.

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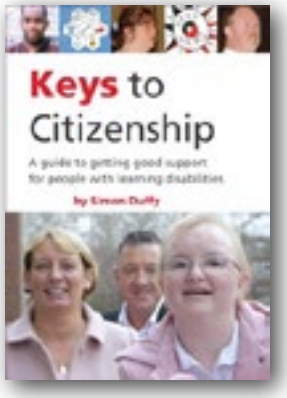

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