Close down the ATUs

Submission to the Joint Committee on Human Rights by the Centre for Welfare Reform

by Dr Simon Duffy

Introduction

The information in this submission has been gathered by the Centre for Welfare Reform. The Centre is a citizen think-tank, totally independent of government and business. Its thinking is based on the practical experience of people working directly to try and create a world where everyone matters. It has over 100 Fellows, many of whom have considerable experience in enabling people to leave institutions. It is a member of Citizen Network, which works with 150 organisations from around the world to advance inclusion and human rights for all.

We can't hope to speak on behalf of the thousands of people with disabilities who have experienced institutionalisation. Nor can we speak for all the families who have suffered and seen their children suffer. However the testimony that you have already heard from people and families honours their experience, which is utterly typical of the current reality (JCHR 2019b).

Our submission is based on the practical and policy questions that arise when trying to help people avoid, leave or close institutions. Primarily, this work is carried out by disabled people, families and their allies - people working at the grassroots, not in positions of power and influence. It is by sharing some of the lessons from this practical work that we hope to illuminate the reality of the ATU problem.

First, it is important to note that the term Assessment and Treatment Unit (ATU) is misleading. ATUs do not provide assessment or treatment, they provide containment and imprisonment. Second, there are many other residential services, which, although not called ATUs, effectively share the same features as these institutions: where you are excluded from ordinary life and where the pattern of your life is controlled by others. Much of our submission could relate to any or all of these other institutions; however we will use the term ATU for convenience.

We are very pleased that the Committee for recognises that this truly is a human rights crisis. Institutionalising children or adults with disabilities is absolutely wrong. It is never necessary and the fact that it is happening - in some places even increasing - is because of problems that can be solved.

But these solutions will only be created if there is the necessary will and integrity. In particular we need to pay much more attention to the forces at work that promote institutionalisation and undermine effective community support.

As a society, we have a choice:

We can continue to fund and organise what is in effect a multi-million pound system of pointless and abusive corporal punishment: scarring children and adults, and achieving nothing positive.

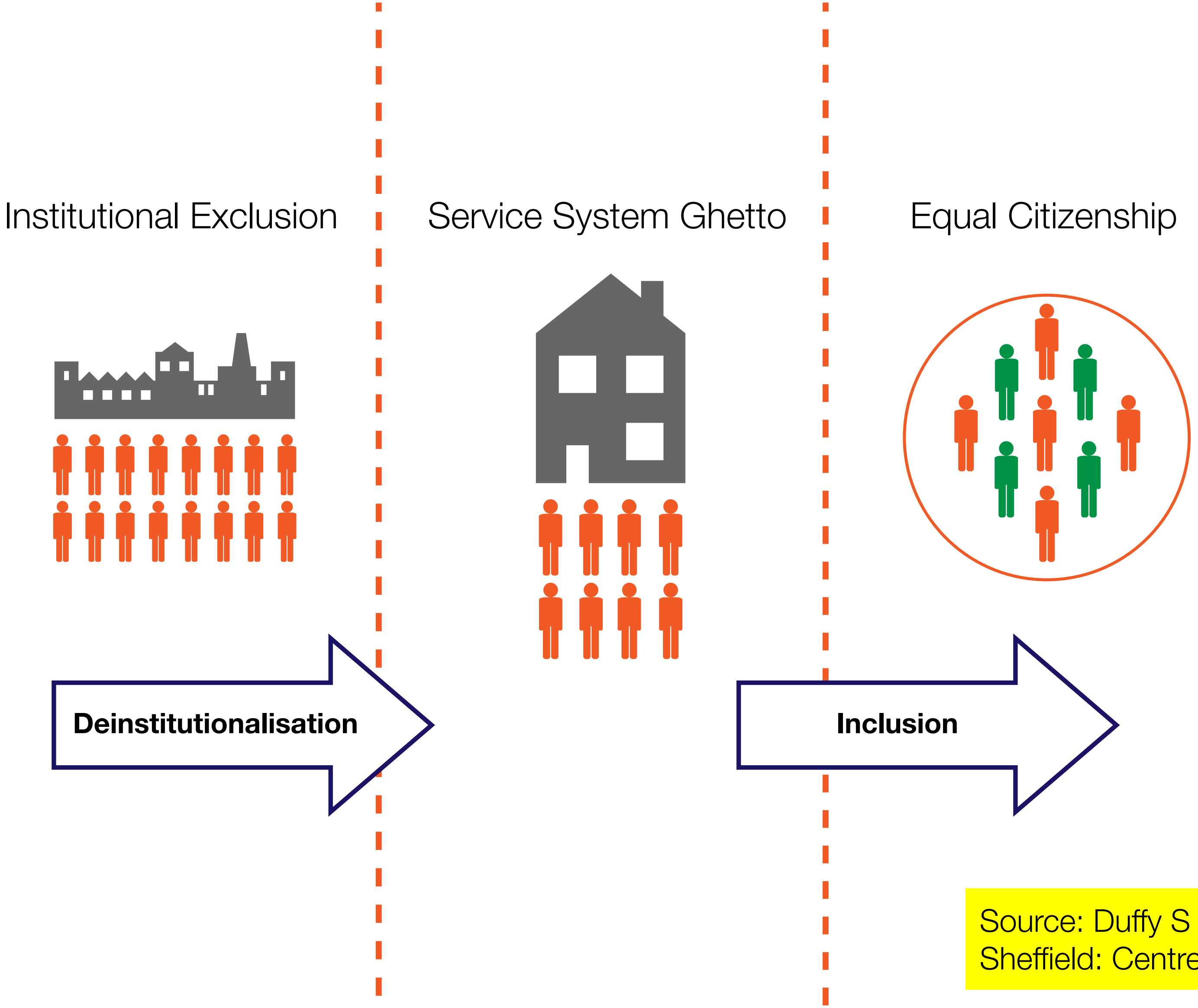
Or, we can commit ourselves to close this system down.

There is no halfway house.

1. Unfinished deinstitutionalisation

It is important to see the current challenges in terms of long-term history of exclusion and discrimination that disabled people and their families have experienced. We are only halfway along a journey to equal citizenship for disabled people and it is the combination of our long-term systemic failure to properly reform social care, combined with the severity of Austerity, which means that there is growing pressure to exclude and institutionalise people.

During the 1960s and 1970s the disability and family movements created the pressure that finally led to the closure of long-stay institutions, which at their peak contained 65,000 people with learning disabilities and many more people with mental illness (Duffy, 2014a). The process of deinstitutionalisation began in the 1970s and by 2010 all the old large long-stay institutions for people with learning disabilities in England were closed (Brend, 2008). However, during this process, a small number of people were not deemed capable of returning to the community. So the NHS established its own units, which were meant to be for short-term care (so-called, Assessment & Treatment Units or ATUs). In addition it encouraged some of its staff to set up segregated residential care services. The NHS then purchased placements from these services, for those people who were seen as having “challenging behaviour.” Over time, these units



Institutional Exclusion

Service System Ghetto

Equal Citizenship

Deinstitutionalisation

Inclusion

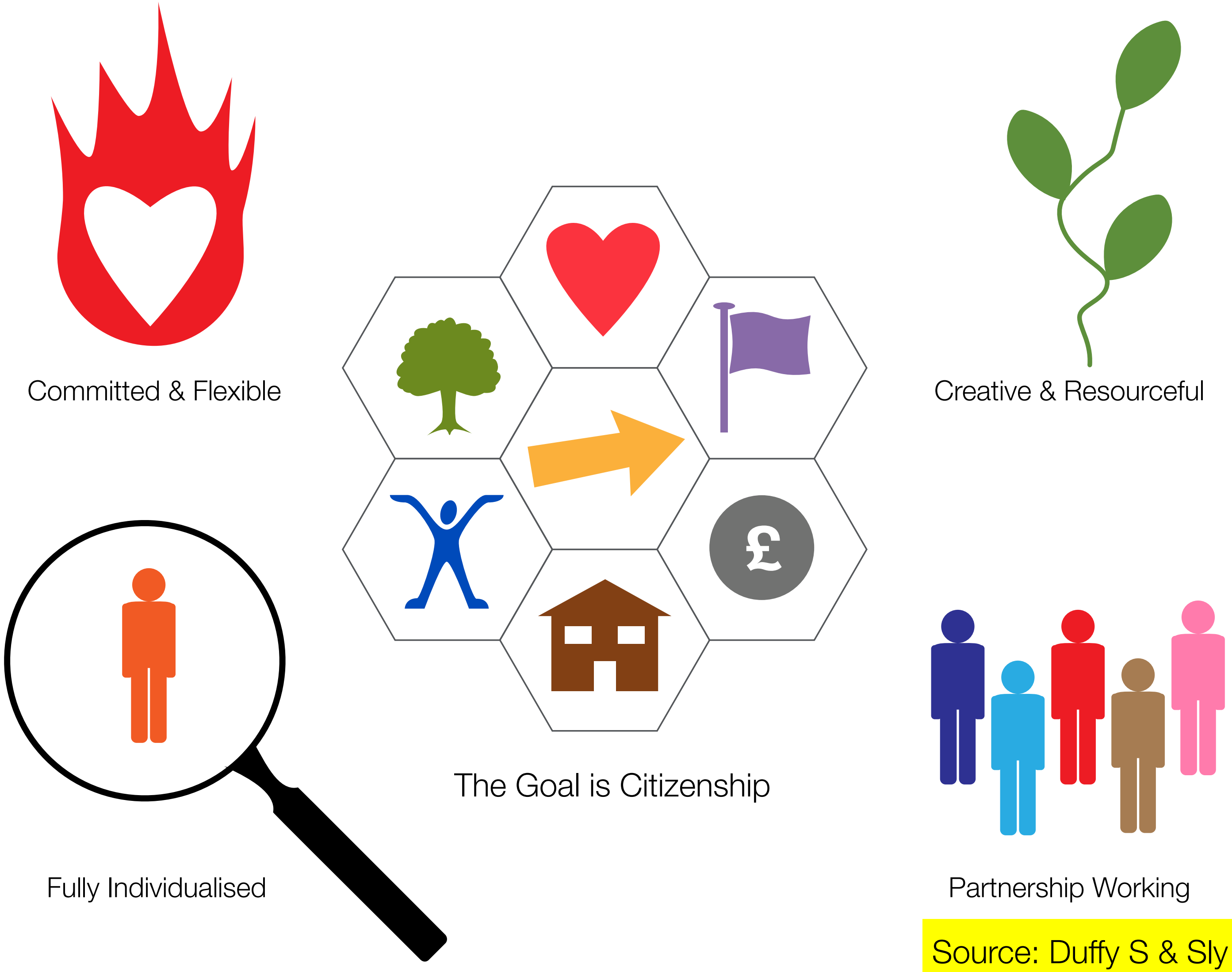
Deinstitutionalisation: As institutions were closed they were often replaced by segregated services - ghettos - the challenge is to create real inclusion and equal citizenship.

Source: Duffy S & Perez W (2017) Keys to Citizenship. Sheffield: Centre for Welfare Reform have been highly profitable and many have been sold-off to private investors and US healthcare companies.

As the NHS transferred funding responsibilities to local government the people left marooned in these units became know as “out-of-area placements.” Moreover there has been ongoing uncertainty about whether people in these places should be funded by local government or by the NHS and this has added to the problem: **If someone’s needs can be identified as a healthcare need then they will be funded by the NHS**. However often this effort to reinterpret a need as a healthcare need is both dubious and dangerous. Also, particularly in some placements, if that person does return to their community then this extra money stays in the NHS. In other words, funding is linked to the provision of institutional care, rather than to the individual or to their home community. This system then creates a perverse incentive for increased institutionalisation.

Interestingly in Scotland, which was slower to start closing its long-stay institutions, than England, there were important efforts to avoid these kinds of out-of-area placements, ATUs and other forms of extreme institutionalisation. A number of organisations were developed to offer extremely **personalised support**, in partnership with people and families. This model of personalised support enables people to manage risk, reduce challenging behaviour and avoid institutionalisation all together. Unfortunately this model of support has not been widely adopted in England (Fitzpatrick, 2010; Animate 2014; Duffy & Sly 2017).

During the period of 2001-09 the Government established a policy leadership process for people with learning disabilities (in England) called *Valuing People*. However, while some



Committed & Flexible

Creative & Resourceful

The Goal is Citizenship

Fully Individualised

Partnership Working

Personalised support means supporting people's citizenship by working in partnership with commitment, creativity and fully individualised support.

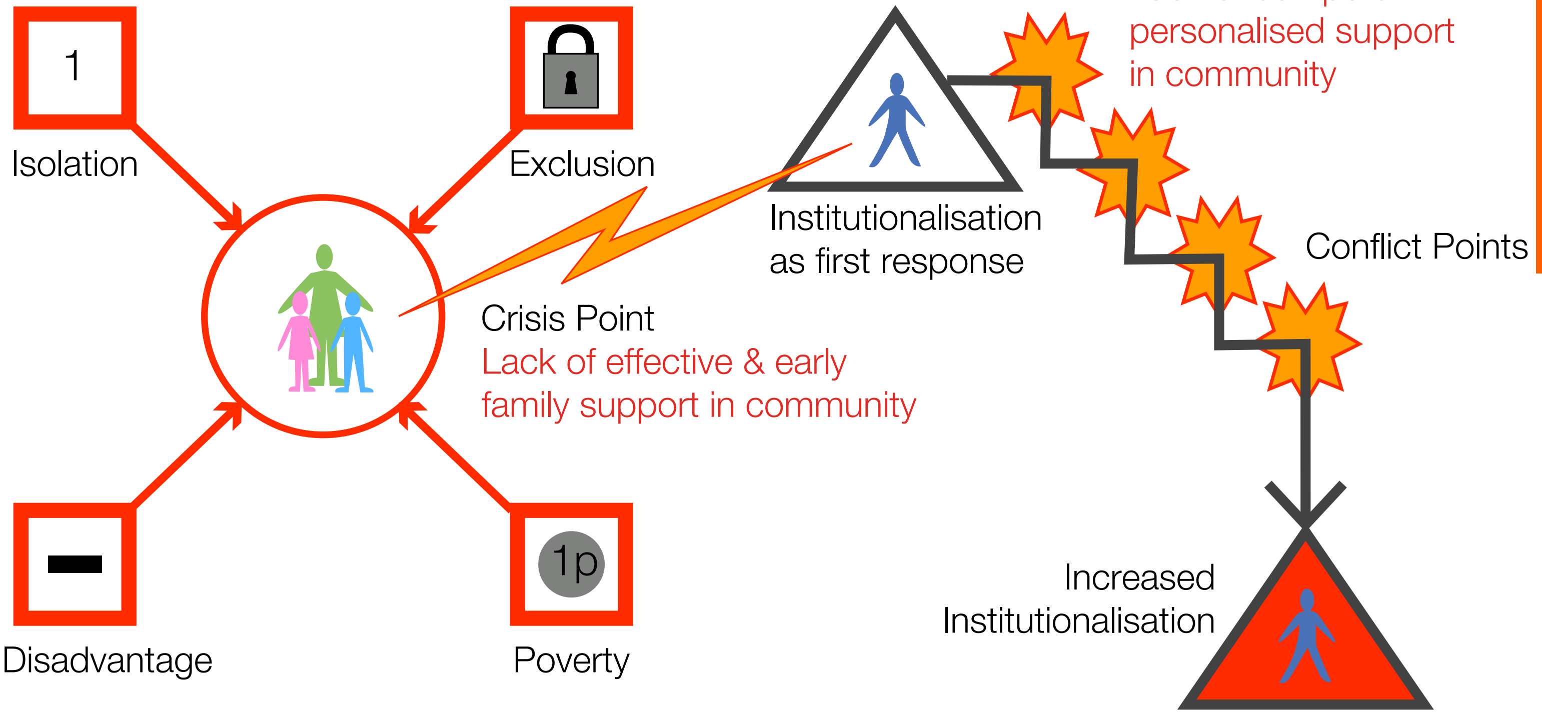
Source: Duffy S & Sly S (2017) Progress on Personalised Support. Sheffield: Centre for Welfare Reform.

attention was given to the problem of out-of-area placements, the main priority was to close the remaining long-stay institutions. The on-going problem of extreme institutionalisation and the use of ATUs and out-of-area placements only became a serious policy priority after the Winterbourne Review scandal of 2011, when the TV programme *Panorama* uncovered the horrific and systematic abuse of the people living in this private institution.

Unfortunately, since the closure of the *Valuing People Support Team,* there has been a vacuum of leadership within Whitehall. Accountability for tackling this problem has been unclear. However, there have still been a number of policy initiatives under the name *Transforming Care*. Unfortunately this programme seems, largely, to have failed in its objectives. Despite all the extra funding and good intentions the number of children placed in ATUs has doubled since 2015 (Hatton, 2019b). Also, the targets set to reduce adult placements have not been met and there seems a strong likelihood that even the very modest progress that is reported is exaggerated. It seems that many people are being being moved - not back home - but into moderately less institutional services (Hatton, 2019c).

This problem is not getting worse because children or adults with learning disabilities or autism are getting more complex. The problem is getting worse because the system is getting worse.

There are too many different problems to cover in detail in our submission; however we hope to focus on some of the most important barriers to progress and how these barriers can be overcome.



Isolation

Exclusion

Disadvantage

Poverty

Crisis Point
Lack of effective & early
family support in community

Institutionalisation
as first response

Lack of competent
personalised support
in community

Conflict Points

Increased
Institutionalisation

People end up in private hospitals with challenging behaviour reputations because of a failure to support families and provide personalised support

Source: Duffy S (2013) Returning Home: piloting personalised support. Sheffield: Centre for Welfare Reform.

Most importantly we'd like to encourage the Committee to understand the systemic nature of these problems.

It is only the light of a truthful and deep understanding of the issues that we can hope to make a meaningful difference. In fact what is true at the level of the whole system is true at the level of the individual - it is only when we **truly listen to what the person and their family are experiencing** that we can hope to provide useful assistance.

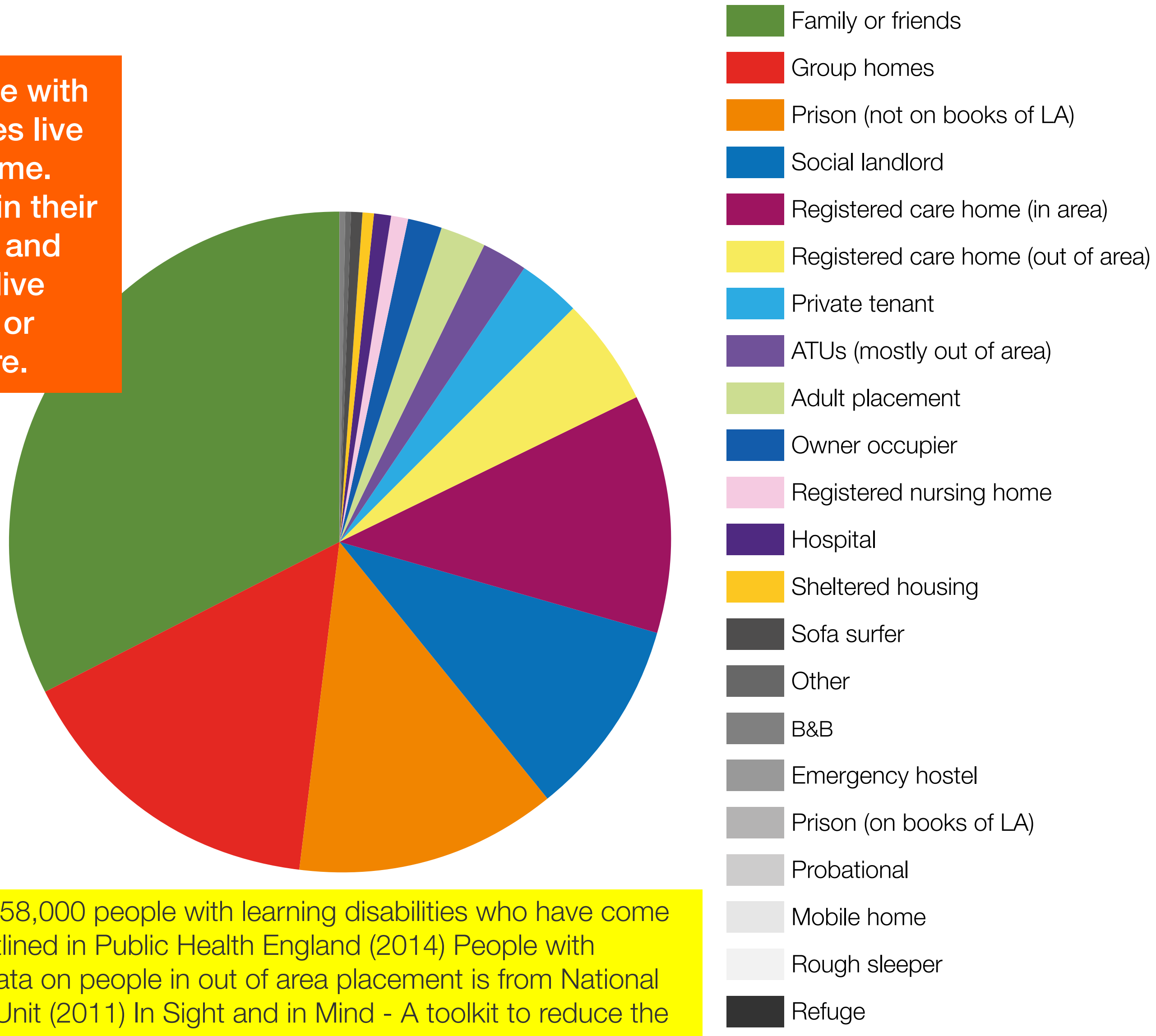
2. There is no need for ATUs

The gravest danger for people who end up inside these institutions is that people start to believe they must be there for a good reason and that it is the complex needs of the person that require these extraordinary measures, at such an extraordinary cost. However, just because an institution exists - and just because people are sent there - does not mean the institution is necessary.

In the official testimony provided to the Committee there was mention of the “in-patient treatment” happening inside ATUs (JCHR 2019a). But can a reasonable assessment be carried out when someone is taken away from their family and community and placed in an environment where they will naturally become angry or depressed? What treatment can be provided in a custodial environment, other than boredom, tranquillisers and multiple forms of control or punishment?

These children and disabled adults are not ill - they may be upset, confused or angry - but they are not ill. They do not need treatment but understanding, communication, control, good support and a home where they are safe and can begin to develop to their full potential. If is helpful to describe some of these young people as having mental health problems, then it seems very likely that much of this is a result of the scarring experiences they have undergone on their journey into these institutions.

Only 23,845 people with learning disabilities live in their own home. 35,340 do not live in their own community and 77,470 people live in institutional or residential care.



Sources - This data covers 158,000 people with learning disabilities who have come to the attention of LAs as outlined in Public Health England (2014) People with Learning Disabilities 2013. Data on people in out of area placement is from National Mental Health Development Unit (2011) In Sight and in Mind - A toolkit to reduce the use of out of area mental health services. London, National Mental Health Development Unit. Plus prison data.

An earlier witnesses before the JCHR makes this clear:

> "I did not know what was happening. Looking back at it now, it does not feel real. It feels like some sort of nightmare. It was not a safe place. It was not a treatment room. I got no assessment or treatment done. There was no care. I was just put in this room, and I lay there and went to sleep. How can you put drugs in people like that? I do not understand that part of it and I still do not." (JCHR, 2019b)

The history of institutionalisation teaches us that these kinds of places never work and that they always become abusive (Keilty & Woodley, 2013). Most of the harm that is done is never adequately captured because it happens behind closed doors and is carried out by people who do not want to reveal what they are doing. Institutions fabricate a subhuman status for those who are imprisoned within them, and those with power struggle to resist exploiting that power (Goffman, 1961).

Not everyone working inside these institutions is an abuser; but the environment is abusive and the temptations to commit abuser are much greater than in ordinary life.

Until 2015 regular data was collected describing the experiences of people in ATUs. It makes for grim reading, particularly as it is based on staff recordings of incidents and almost certainly understates the real situation. For instance, in a 3 month period: **72%** of people were controlled by the use of tranquilliser and over **50%** had experienced self-harm, an accident, a physical assault, restraint or seclusion (NHS Digital, 2016).

When carrying out the research for *Returning Home* we found that amongst the 6 people who had been in an institution and were now hoping to return home: All 6 had suffered sexual abuse, 5 had suffered physical abuse, 2 neglect and 1 financial abuse (Duffy, 2015).

After 2015 the data system was changed, and it is now harder to track what is happening inside these institutions. However Professor Chris Hatton analysed some of the available data and this shows that if anything things are getting worse, with physical restraint growing and with children more likely to be restrained than adults (Hatton, 2018a; 2019a; 2019b).

We do not need ATUs. But ATUs exist because we fail to support people in the right way, and when things get out of control people panic and react from fear. ATUs are not about assessment and treatment, they are primarily about containment. But these institutions are worse than prison. As the poet Joseph Brodsky, somone who experienced both, put it:

> “in prison at least you know where you stand. You have a sentence - till the whistle blows. Of course, they can always tack on another sentence, but they don’t have to, and in principle you know that sooner or later they’re going to let you out, right? Whereas in a mental institution you’re totally dependent on the will of the doctors.” (Jospeh Brodsky in Volkov, 1998 p. 68)

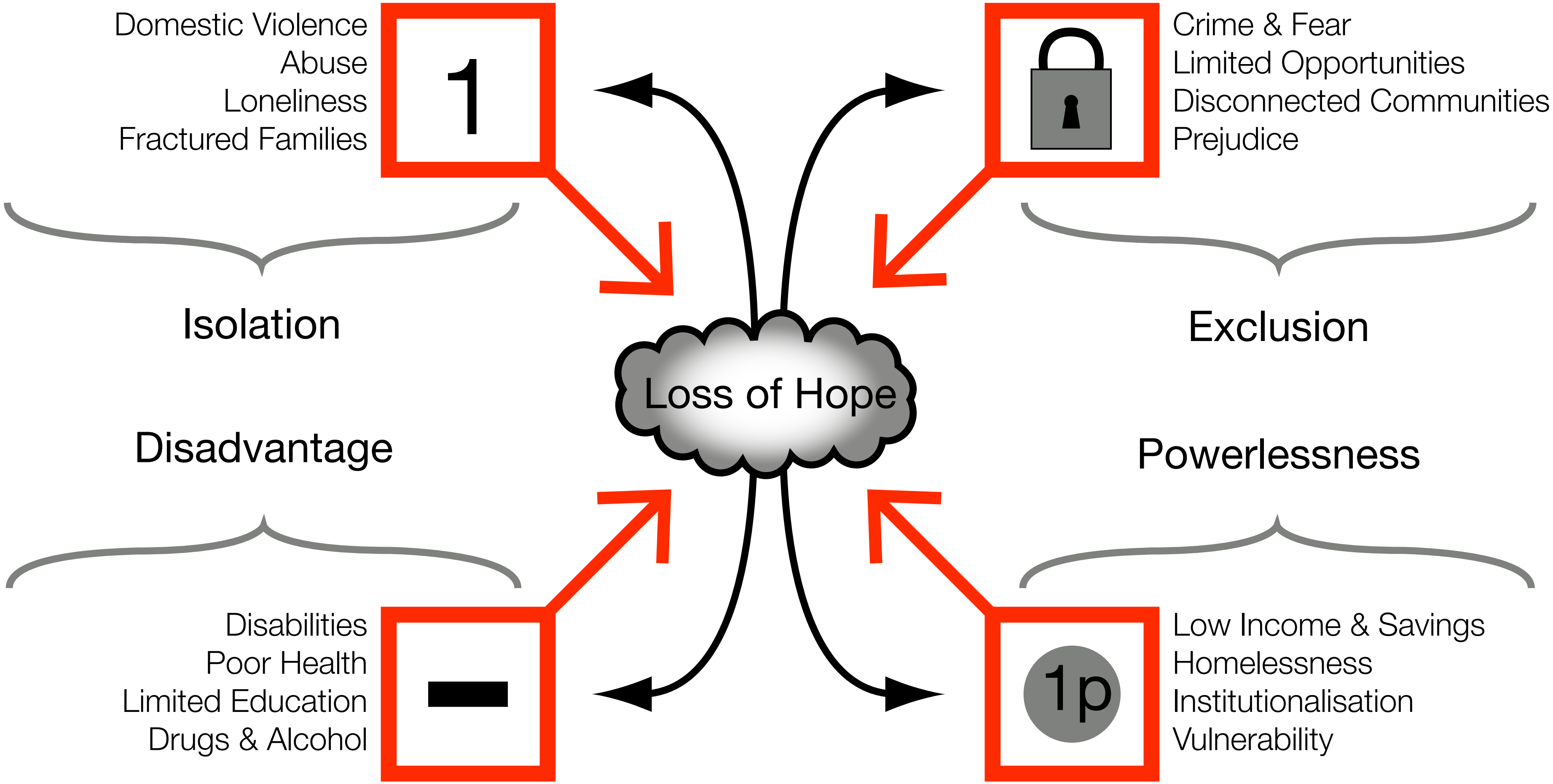
We do know how to successfuly support people with complex needs, communication difficulties, learning disabilities or autism. Each individual is different and it is not helpful to try and enforce a standardised services upon people; instead we need to help people design the support they need around their needs, gifts and potential. It is has been our ongoing failure to provide this flexible and personalised support that has created the current crisis. This is a very soluble problem.

3. Austerity makes everything worse

As we mentioned above, ATUs, out-of-area placements and institutional placements have existed for a long-time. However there does seem to be significant evidence that these problems are getting worse under Austerity.

We realise that it goes far beyond the scope of the JCHR to end Austerity. But it is worth reflecting on Austerity's severe impact on families, and on a social care system that is supposed to provide the essential community support needed to avoid institutionalisation. For instance the services that are supposed to support people in greatest need - social care services - have been cut more than any other public service. Adult Social Care in England has cut the number of people it serves from 1.8 million in 2009 to just over 1.0 million in 2017 (NHS Digital, 2010-2018).

Meanwhile there are similar cuts in children services; whilst the number of children being taken away from their families and placed into care has continued to grow. Alongside these reductions in community support it is important to recognise that many families are also having to deal with reduced benefits, poorer housing, increasing and changing assessments, hunger and poverty (Duffy, 2014b; 2018). It is the unbearable stress placed on a family, partly caused by Government policy, that undermines the family's ability to cope.



Domestic Violence
Abuse
Loneliness
Fractured Families

Isolation

Crime & Fear
Limited Opportunities
Disconnected Communities
Prejudice

Exclusion

Loss of Hope

Disadvantage

Disabilities
Poor Health
Limited Education
Drugs & Alcohol

Powerlessness

Low Income & Savings
Homelessness
Institutionalisation
Vulnerability

Real Poverty:
Poverty is the lack of all the resources necessary to participate as an equal in the life of the community

Source: Duffy S & Hyde C (2011) Women at the Centre.
Sheffield: Centre for Welfare Reform

To avoid unnecessary institutionalisation it is particularly important that local statutory bodies can:

- **Form supportive and on-going relationships with people and families**
- **Use flexible funding to access appropriate housing solutions in all housing markets**
- **Respond quickly to offer flexible forms of respite**
- **Support the development of wider networks of support**

Without flexibility and the ability to tap into local resources then an institutional response becomes almost inevitable.

In principle *Transforming Care* did recognise that investing in local services was essential. However the nature of Austerity means that it has been those very services, the most local, preventive and flexible services, the ones that help people avoid institutional care, that have been the first to be cut.

Local authorities and the NHS cannot avoid paying for institutional services, often at growing cost, and so they must sacrifice local family and community support in order to pay for them. This creates a vicious circle which further accelerates the growth of institutional provision. Trying to achieve *Transforming Care* in the context of Austerity is truly a Sisyphean task. No new investment in community services can compensate for the the billions that have already been cut from those same services.

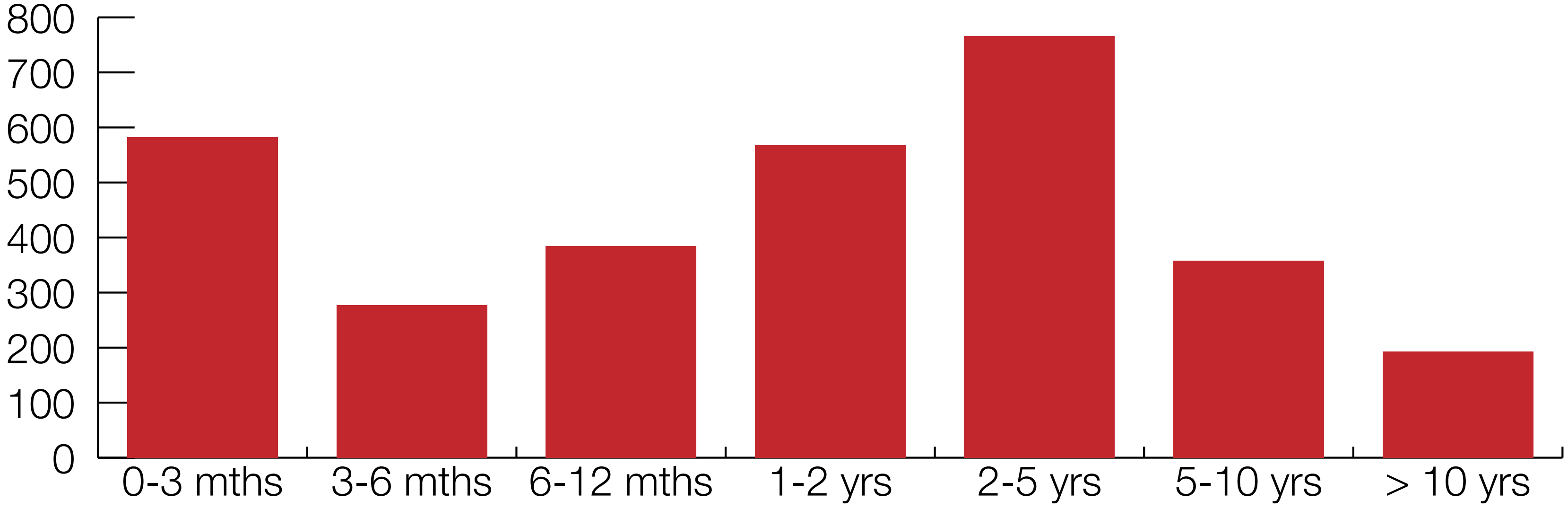
However the institutionalisation problem did exist before Austerity and there are things we can do to reduce the problem now.

4. ATUs exists because of system failure

When working with families whose children had been placed in Winterbourne View we found that institutional placements occurred as part of a consistent pattern (Duffy, 2013):

1. Families, who had not received any support they could control or tailor to their needs, had experienced a crisis which meant that they needed extra help to support their child.
2. The system responded by only offering some form of institutional care e.g. residential respite, care home, residential school.
3. The person would be angry and upset at having to leave their family and at the restrictions placed upon them in the new service, and so would act out.
4. The service would fail to cope and then demand that the person be moved somewhere else.
5. The system would place the child further away from home in a more institutional and controlling environment.
6. This pattern would then repeat on a loop until the child had reached the ultimate institutions we call ATUs.
7. Eventually children and adult might be moved out of the institution, but often only into another institution. This pattern goes by the rather horrible name of "churn."

Length of stay for people with learning disabilities in inpatient 'facilities' - Note that this describes length of stay in a particular institution - people are often moved from place to place and so many people will have been away from home for many years longer.



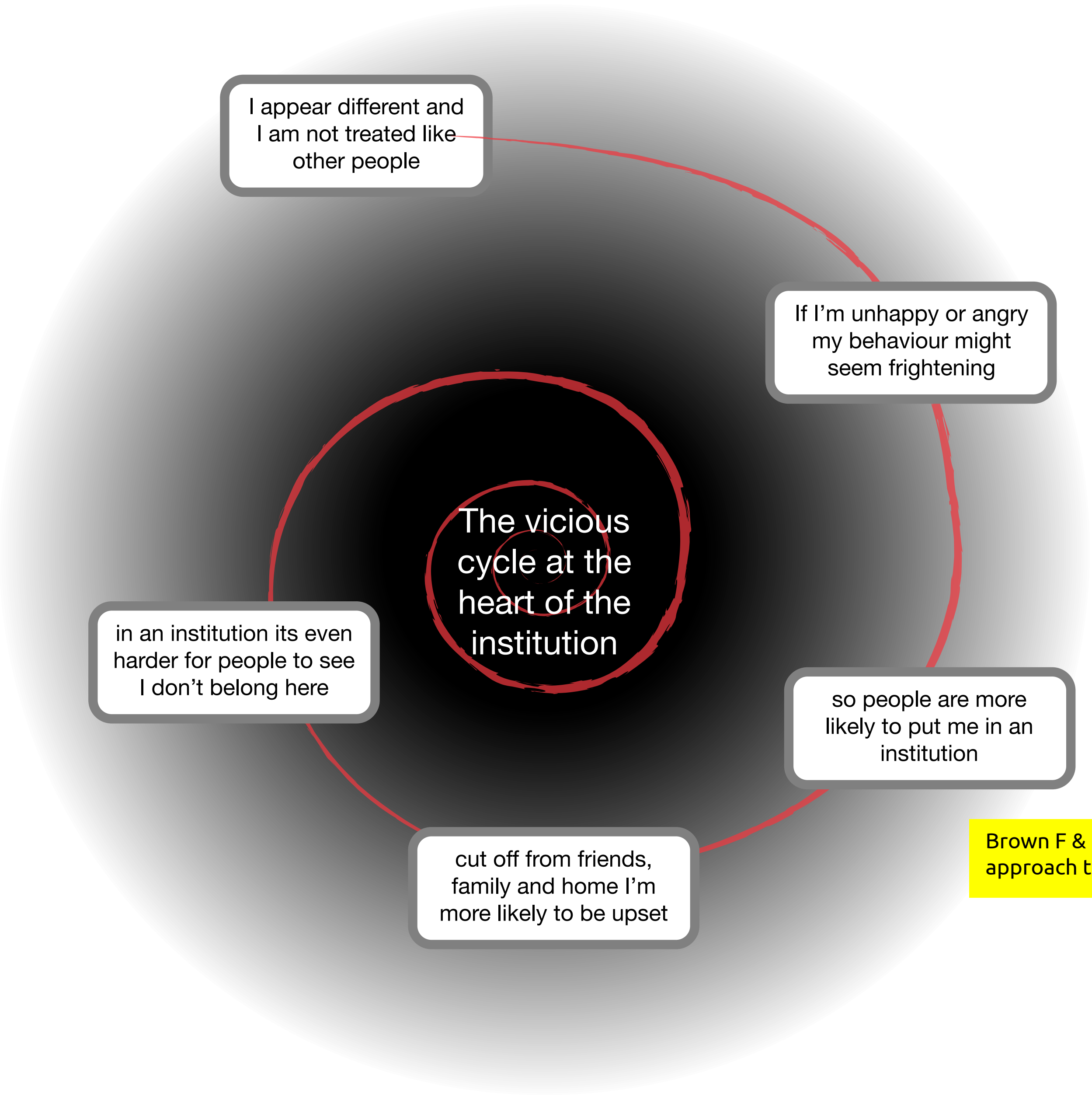
Source: Learning Disability Census, 2013. n=325

It is important to understand that this process almost always escalates because of factors that are entirely external to the child or adult. The person is usually reacting to something they don’t like or communicating in a way that provokes an unhelpful reaction from people who don’t understand them. Families usually already have coping and support strategies - but the system often fails to listen to and respect the family’s perspective. This does not mean that providing good support is always easy - it often requires thought, understanding and creativity, which can be lacking.

Good support will always be more effective and efficient than bad support - but providing good support is not the default setting of the current health and social care system. The default setting is institutional care - by this we do not just mean ATUs - but all the care homes, residential schools, colleges, day centres, care services that consume of the most social, health and education funding for children and adults. Sadly we also know that the kind of abuse we see happening in ATUs, is also common in other care settings (Ward, 2018).

The ATUs is the peak institution - but it is the peak of a system which is **institutional** in its character. The institutional pattern, which assumes the powerlessness of the person and the family, begins with regulated and inflexible home care services and then spreads with growing toxicity all the way to the ATU. The system is over-regulated, over-specified and institutionalised, so that most people cannot imagine how to begin to offer something better.

The driving force in this downward spiral is **fear**. Professionals do not want to take responsibility for designing new solutions when they might make mistakes. Instead they seek others who will take on those responsibilities, and there is strange comfort - even if it comes at a great financial



The vicious cycle at the heart of the institution

I appear different and I am not treated like other people

If I'm unhappy or angry my behaviour might seem frightening

so people are more likely to put me in an institution

cut off from friends, family and home I'm more likely to be upset

in an institution its even harder for people to see I don't belong here

There is a vicious cycle at the heart of the institution which can easily pull people down and trap them for years

Brown F & Dalrymple J (2018) A New Way Home: A personalised approach to leaving institutions. Sheffield: Centre for Welfare Reform.

cost - in moving people further away from home into more expensive and more institutional services and no longer having to take personal responsibility for that person's care. It is important to recognise the psychological factors which drive institutionalisation.

The key to ending institutionalisation is to reverse this pattern and to help people and families develop their own solutions and to organise the relevant supports and services around their individual and family needs.

5. Support must be family-based

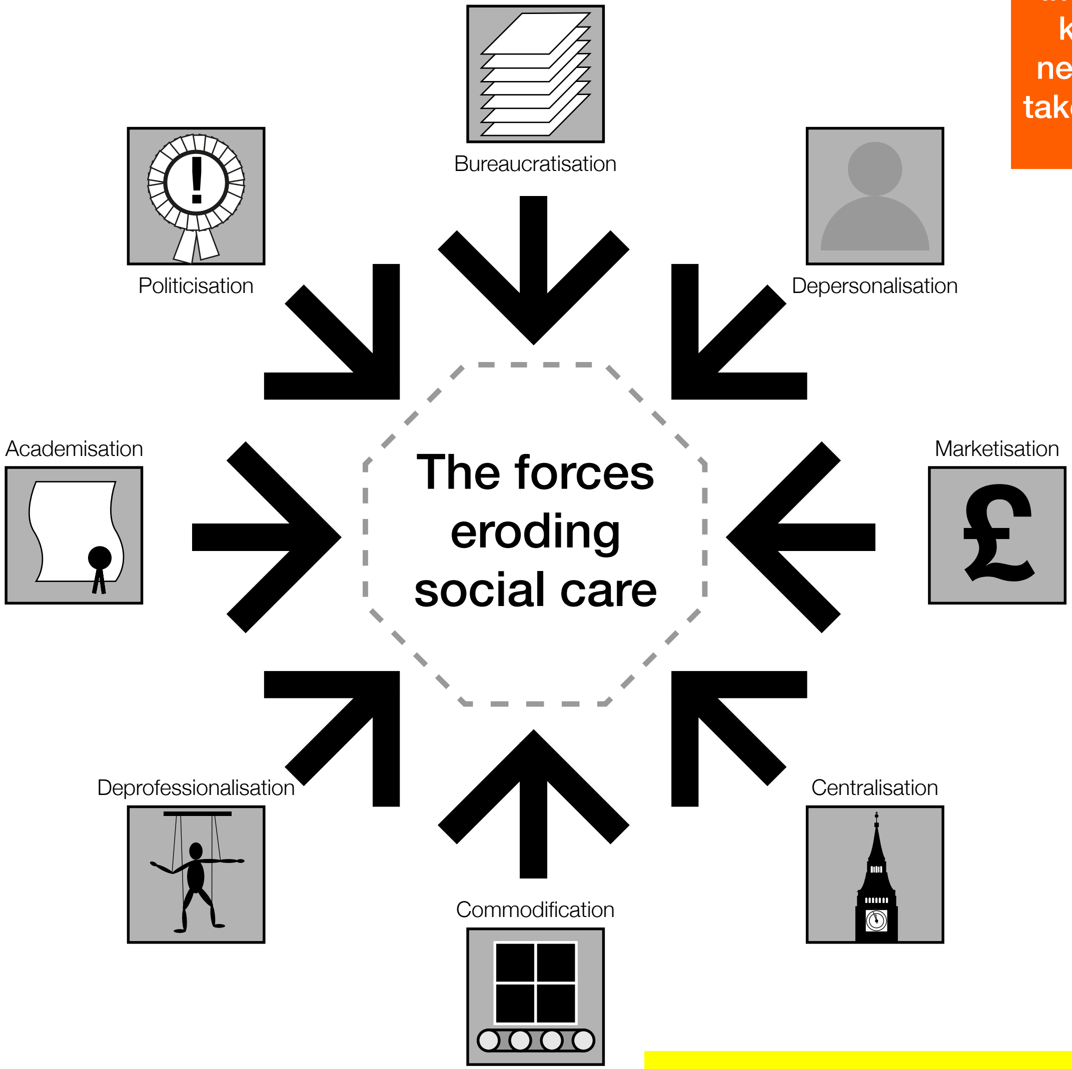
We need to change the delivery and organisation of social care for children and adults. This means putting power and control in the hands of people and families and giving them the support to create the solutions they need.

- **Design and organise meaningful and flexible support**
- **Craft systems of support, communication and risk management**
- **Ensure families and people are in control**
- **Employ the right staff**
- **Find suitable housing solutions**
- **Be creative and aspirational**

The system has been talking about these ideas for some time and the Care Act 2014 tried to establish them as working principles. But there is much more to do to make them real. Ultimately this is about giving people permission to use all their available resources as flexibly as possible and giving people support to make their own decisions. The system currently does not do this.

Ultimately the cause of this crisis is a systemic failure in how we organise health and social care. We can get this right, in fact many existing policies - if they were actually properly implemented - would radically reduce the current problem.

The social care system is increasingly unable to offer the kind of support people really need as mechanistic processes take over and the unique value of each individual is lost.



The forces eroding social care

Bureaucratisation

Depersonalisation

Marketisation

Centralisation

Commodification

Deprofessionalisation

Academisation

Politicisation

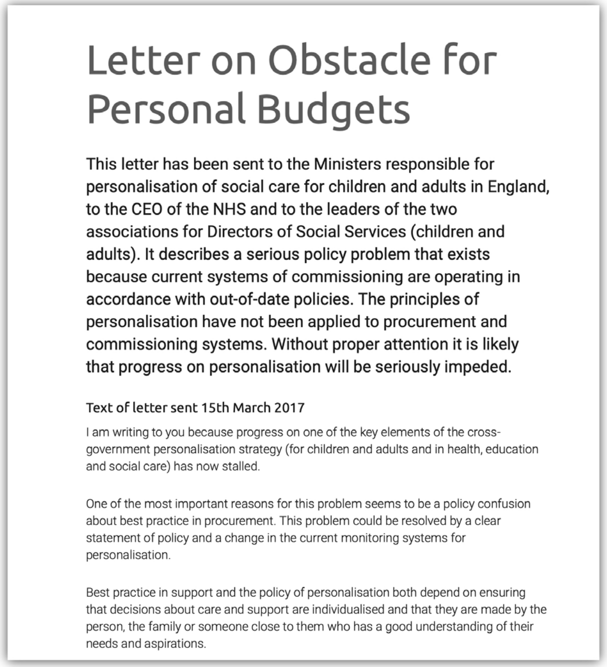
Source: Jackson R (2018) Reforming Social Care:
Time for radical change. Sheffield: Centre for Welfare Reform.

Key measures that would make a big difference include:

1. Establish Local Area Coordination or some other place-based system of social work and community support in order to help grow the community's capacity to solve problems early (Broad, 2012). Systems that wait for crises to happen before offering support will generate crises; but this early support must be rooted in community life - not in service-based solutions.
2. The default setting for the system who need support must be that they are supported to take control and design their own support, select their own support provider, advisor or advocate. Currently people are forced to either accept the models imposed by the state (which tend to be highly institutional) or they are expected to take on all responsibility of managing a direct payment and organising their own support. This is a foolish system which fails to offer people the right kind of support when they need it. The use of systems of brokerage, personalised support and Individual Service Funds (ISFs) would bridge these two extremes (TLAP, 2015).
3. Reverse the procurement guidance which insists that local authorities tender for health and social care services. Instead allow people, families and local leaders to organise how community support is developed. Local authorities should establish the system of personalised commissioning originally envisioned by the Care Act 2014 and allow people and families flexible personal budgets without having to take on a direct payment. Good solutions are evolved - not commissioned - and the system needs to be changed to protect and support the relationships that make positive change possible.

On 15th March 2017 we wrote to the Department for Health and others to outline the serious policy barriers to making the objectives of the 2014 Act and the personalisation policy real. While the relevant Ministers responsed the issues described in the letter have still not been resolved: yet they are straightforward policy issues simply requiring clear and public guidance:

https://www.centreforwelfarereform.org/library/by-az/letter-on-obstacle-for-personal-budgets.html



Letter on Obstacle for Personal Budgets

This letter has been sent to the Ministers responsible for personalisation of social care for children and adults in England, to the CEO of the NHS and to the leaders of the two associations for Directors of Social Services (children and adults). It describes a serious policy problem that exists because current systems of commissioning are operating in accordance with out-of-date policies. The principles of personalisation have not been applied to procurement and commissioning systems. Without proper attention it is likely that progress on personalisation will be seriously impeded.

Text of letter sent 15th March 2017

I am writing to you because progress on one of the key elements of the cross-government personalisation strategy (for children and adults and in health, education and social care) has now stalled.

One of the most important reasons for this problem seems to be a policy confusion about best practice in procurement. This problem could be resolved by a clear statement of policy and a change in the current monitoring systems for personalisation.

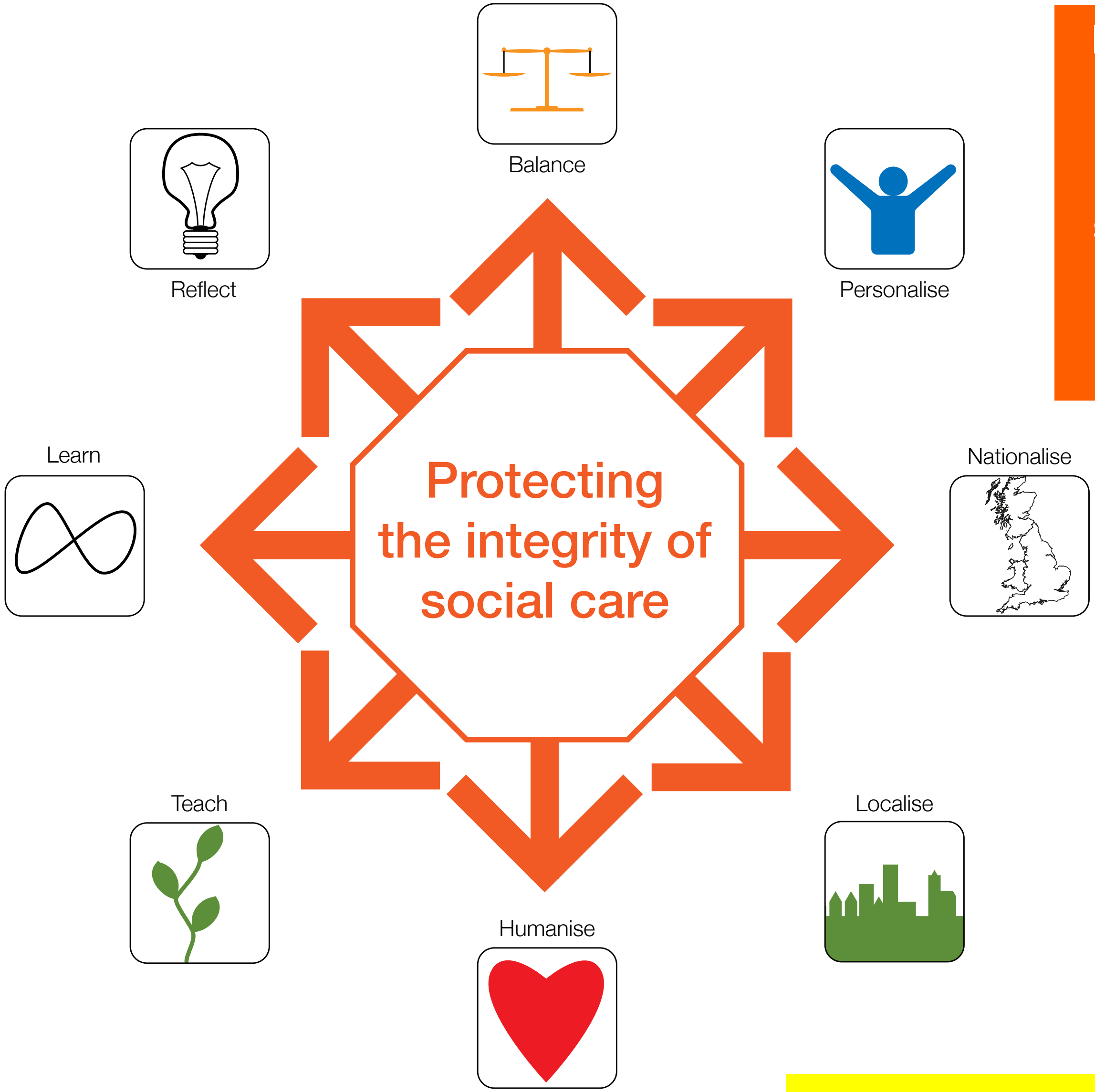
Best practice in support and the policy of personalisation both depend on ensuring that decisions about care and support are individualised and that they are made by the person, the family or someone close to them who has a good understanding of their needs and aspirations.

6. Create a solution-focused culture

We need to grow capacity and understanding across the whole community. This means a whole new approach to education in social work and learning disability nursing; but more profoundly we need to think about education for everyone and the importance of using families and disabled people as educators - leading a changing understanding of what is possible.

We currently behave as if care and support is largely a professional function. However people and families provide **5 times more support** than the funded social care system. Moreover, families are almost always more expert in the needs of their family members than professionals. Professional skills and experience can be very helpful - but only of it is used to cooperate in producing practical solutions by working with people on equal terms.

Currently there is not just a failure to listen to people and families - there is a failure to know what to do if you did listen. For instance, *Transforming Care* data suggests that the majority of families do get some kind of advocacy. However experience of these advocacy systems suggests that they are inadequate. In particular there are serious concerns about their independence. Increasingly advocacy has become directly controlled and funded by the



Protecting the integrity of social care

Balance

Personalise

Nationalise

Localise

Humanise

Teach

Learn

Reflect

It is time for radical reform of social care - this is not just about creating a properly funded universal service - we also require a change in culture to bring humanity to the whole system.

Source: Jackson R (2018) Reforming Social Care:
Time for radical change. Sheffield: Centre for Welfare Reform.

statutory bodies that they are meant to be holding to account. There is no true independence, no separation of powers and often no real expertise - instead a kind of 'going through the motions of advocacy.'

What families really need are good, trustworthy partners who can help with the practical business of finding or developing solutions, who can challenge the system with authority and who will stick with the family through the whole process. It would make more sense to allow families themselves to pick a social worker, service provider, support broker or advocate that they could work with.

Public bodies should be spotting, supporting and championing those practitioners who have the most success in building partnerships and good solutions with families. The current system is too risk-averse and process-orientated. Trying to reduce risk by the use standardised processes only increases the risk of harm.

Practical measures that would make a difference:

1. Treat people and families as experts and pay people to teach and train professionals.
2. Create an education system that treats inclusion as primary goal. End the overly competive and regulated system that drives up exclusions.
3. Reform education for social work and learning disability nursing to encourage practical learning for all on how to support personalised support and community connections, embracing people, families and community workers.
4. Establish a robust and genuinely independent advocacy system - funded separately from the service system and supporting collective self-advocacy for

people and families. Advocacy Networks like PLAN and Vela Microboards offer a good model for growing sustainable long-term support to families.

5. Encourage commissioners to see their role as growing local talent, strengthening and connecting local forms of leadership, enabling innovation and change - not purchasing standardised services by bureaucratic processes, for the lowest possible cost.

7. Money must follow the person

We need to change the systems and incentives in the system to make it harder for systems to institutionalise people and easier for people to move back home. The financial systems are a big part of this and these need to be redesigned.

Currently the system creates a perverse incentive to treat people as an NHS responsibility and to interpret problems as healthcare needs. Given the huge disparity between health and social care funding, where cuts in local government funding have led to a reduction in the number of people receiving Adult Social Care in England from from 1.8 million to 1.0 million this is entirely inevitable.

Even worse, if a person's needs are deemed suitably serious then local health commissioners can get regional commissioners to fund their care.

This systemic failure can be treated as a failure of local capacity - but it is actually a systemic failure created by central government and the failure to resolve long-standing policy issues. Ultimately, local funding must follow the person to ensure that the system has every incentive to bring the person - and the funding back to the community.

The late Professor Jim Mansell who wrote the key guidance to Government on all these issues back in 1993 (and updated in 2007) wrote:

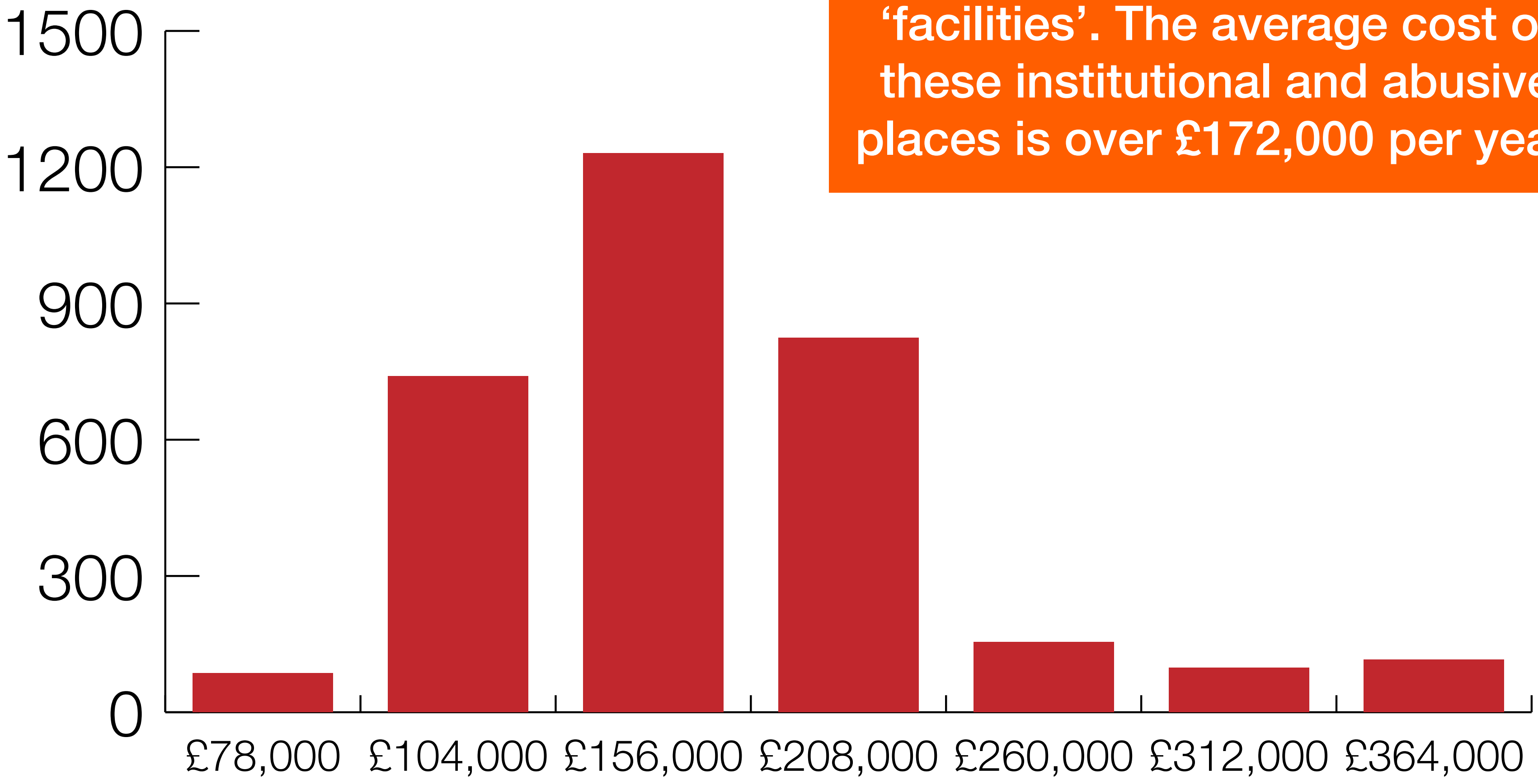
> “The role of the National Health Service is to keep contributing the financial resources needed to sustain the transfer of specialist learning disability services to councils - not to undermine the strategy set out in this report by commissioning poor-quality services, especially out of area, themselves.”

Sadly this guidance is not followed and, for instance, institutional placements for children are funded regionally and so both the council and the local CCG can avoid having to fund support if the child is institutionalised.

Ultimately, we must ensure that funding for local people is under local control. Currently hard pressed local authorities are tempted to let people become the responsibility of a better-funded and centralised NHS. Instead we need a NHS that is accountable to local people and works with communities to develop the community supports that are required to avoid institutionalisation.

There is no reason why almost the whole local NHS budget should not be monitored by the local authority - this would encourage more joined-up solutions and better incentives throughout the system.

In England in 2013 we spent over £0.5 billion on 3,250 people with learning disabilities in inpatient 'facilities'. The average cost of these institutional and abusive places is over £172,000 per year.



Source: Learning Disability Census, 2013. n=3250

8. Centralised regulation doesn’t work

It is always helpful to increase political pressure on government ministers to stay on top of these issues. However the command-and-control style of government in England merely exacerbates the underlying problem. The minister instructs senior civil servants, who instruct junior civil servants, who instruct senior NHS managers, who instruct junior NHS managers, who try to put pressure on their peers in local government.

At the end of this attenuated and ineffective chain of control is the process rather grandly known as ‘commissioning’ but which is effectively the purchasing of care by a bureaucratic process which tends to put funding into the hands of large care providers - those who are good at responding to procurement requests and tenders for care, but who are rarely expert at being partners with people and families or at ensuring people are well supported in their own communities.

Rarely has anyone in this chain of command has any practical experience of providing good community support and by the time the data starts to show the failure of the Minister’s plan the Minister has usually moved on to another job.

In 2014 the then Minister, Norman Lamb, commenting on the failure of the Transforming Care programme, said:

> "The abject failure of some people in the system to do the right thing and change the model of care just makes me all the more determined that we see this through, even though it will take longer than I originally hoped." (Wiggins & Williams, 2014)

But of course, for all this wonderful honesty, by 2015 Norman Lamb was no longer in the Government.

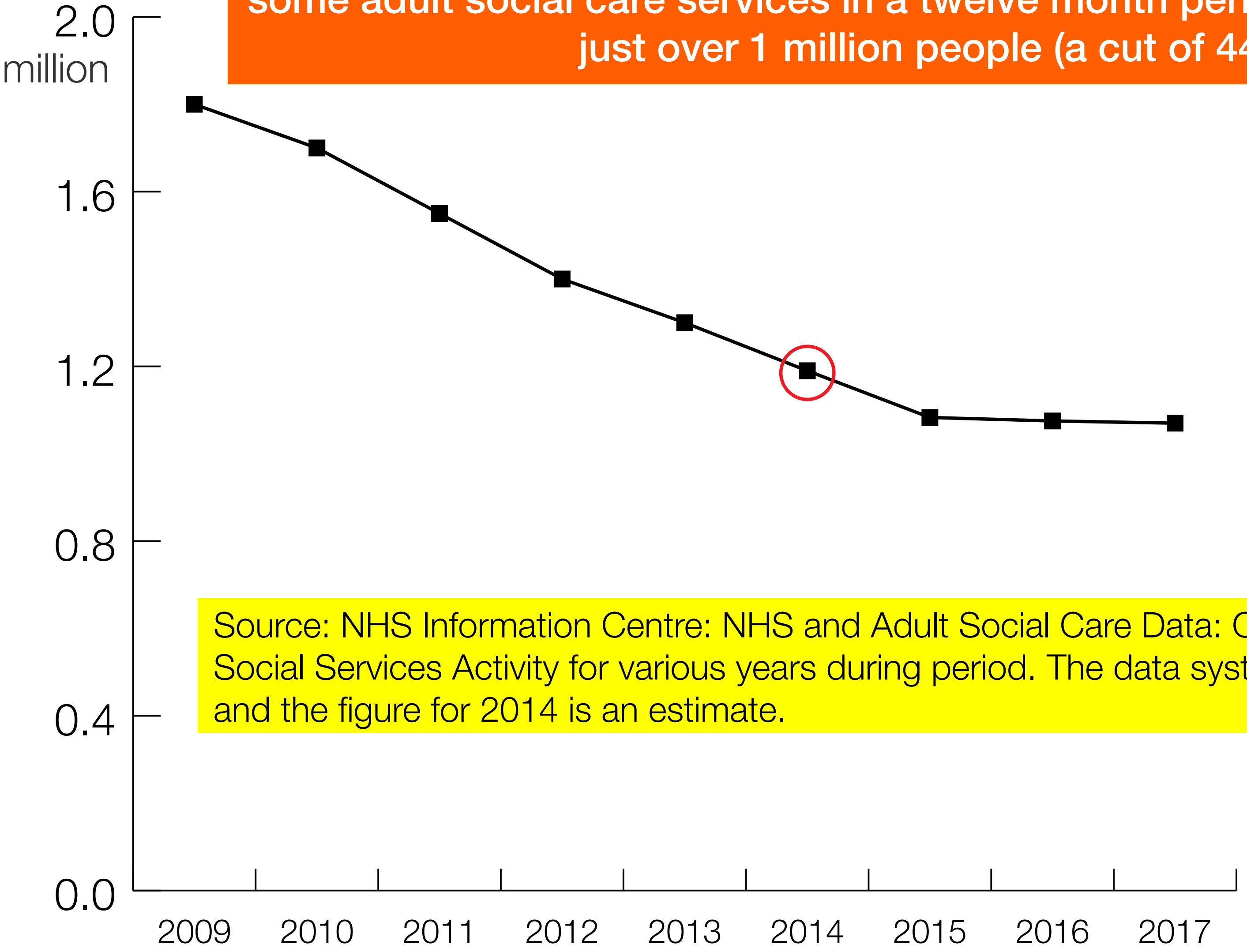
Above all we need government to know its strength and its limits. We need it to use the Law to make that which is wrong illegal. But we also need it to empower those who do the work that can never be done in Whitehall. We need a better understanding of the problem, combined with commitment to tackle the serious systemic factors that create the problem - not more targets or fancy initiatives.

We must increase the accountability of politicians, but primarily it is their accountability for increasing the accountability of others locally that really matters. This means locating responsibility at the frontline and strengthening the effective rights and freedoms of people and families.

This challenges many of the assumptions of the current system - which tries to manage via targets, procedures and regulation. At a deeper level the challenge is to reduce institutionalisation in the whole of the health and social care system and this means distributing, not centralising, power.

For example, greater regulation always seems like a plausible and helpful strategy. But it is not helpful. There is no empirical evidence that regulation increases quality, even in more ordinary

Since 2009 the number of people receiving Adult Social Care in England has fallen, despite growing levels of need. In 2009 1.8 million people received some adult social care services in a twelve month period, today the figure is just over 1 million people (a cut of 44%).



Source: NHS Information Centre: NHS and Adult Social Care Data: Community Care Statistics: Social Services Activity for various years during period. The data system was changed in 2014 and the figure for 2014 is an estimate.

care settings. Worse, we know that regulators constantly fail to spot extreme abuse. In the case of Winterbourne View it was *Panorama* - not the CQC - that discovered the abuse. And when we met with families whose children had been at Winterbourne View they said that Winterbourne View was the “least bad” institution that their children had been placed in. In other words Winterbourne is not an exception - it is the norm. CQC is not changing this and cannot change this.

In fact regulating services effectively normalises them - it institutionalises the institution as an acceptable offer. This is not what we need. We need these institutions to become unacceptable - unregistrable - unfunded - to be closed down.

The Centre has published a number of reports which explain why regulation, particularly the kind of bureaucratic and centralised regulation developed by CQC, is bound to be ineffective and often has perverse effects, undermining some of the community supports that are most effective at keeping people safe (Jackson, 2015; 2017; Burton, 2016; 2017; Zigmond, 2018).

9. Close the ATUs down

It is the view of the Centre for Welfare Reform, based on decades of success in supporting people in the community, that there is no need for institutional care. We need to seriously commit to the closure of all ATUs: Starting with the private hospitals, and then closing statutory services. We need to work with families and service providers to organise alternative provision and we need laws that make it impossible to place people in such institutions.

It was encouraging that Simon Stevens, CEO of the NHS, began the *Transforming Care* programme by publicly committing to close down NHS ATUs. However this policy may not have been very wise. The priority should be to **close down the private-sector institutions first**.

Currently we are seeing the rebirth of the 18th Century “trade in lunacy.” But now it is not wealthy individuals who are paying to remove difficult family members, it is the government who are paying to breaking apart families and place people in private mental institutions. As Ian Birrell describes in great detail we are, in effect, funding foreign companies, to exploit, imprison and abuse children and adults with autism and learning disabilities (2018c). One researcher (Lucy Series) recently reported that these mental hospitals are reporting profits of between 5% and 35%. Investors will continue to put money in these hospitals until the Government states clearly that these are not an acceptable option and must be closed down.

So - as a matter of urgency - the Government must commit to close all private institutional placements and instead only use NHS services. Currently the level of NHS placements is about equal to the Government's target for all the placements that they deem necessary (NHS England, 2015). Therefore, this reform is utterly achievable and simply involves prioritising the closure of private institutions. If a clear commitment like this is made then private investments in institutions will reduce and the corrupt practice of placing people inside private institutions, **where their own psychiatrists can deem them not ready for discharge**, can be ended.

To be clear, it is not that state institutions are any better than private institutions, but if we ban private institutions first and then focus on state institutions:

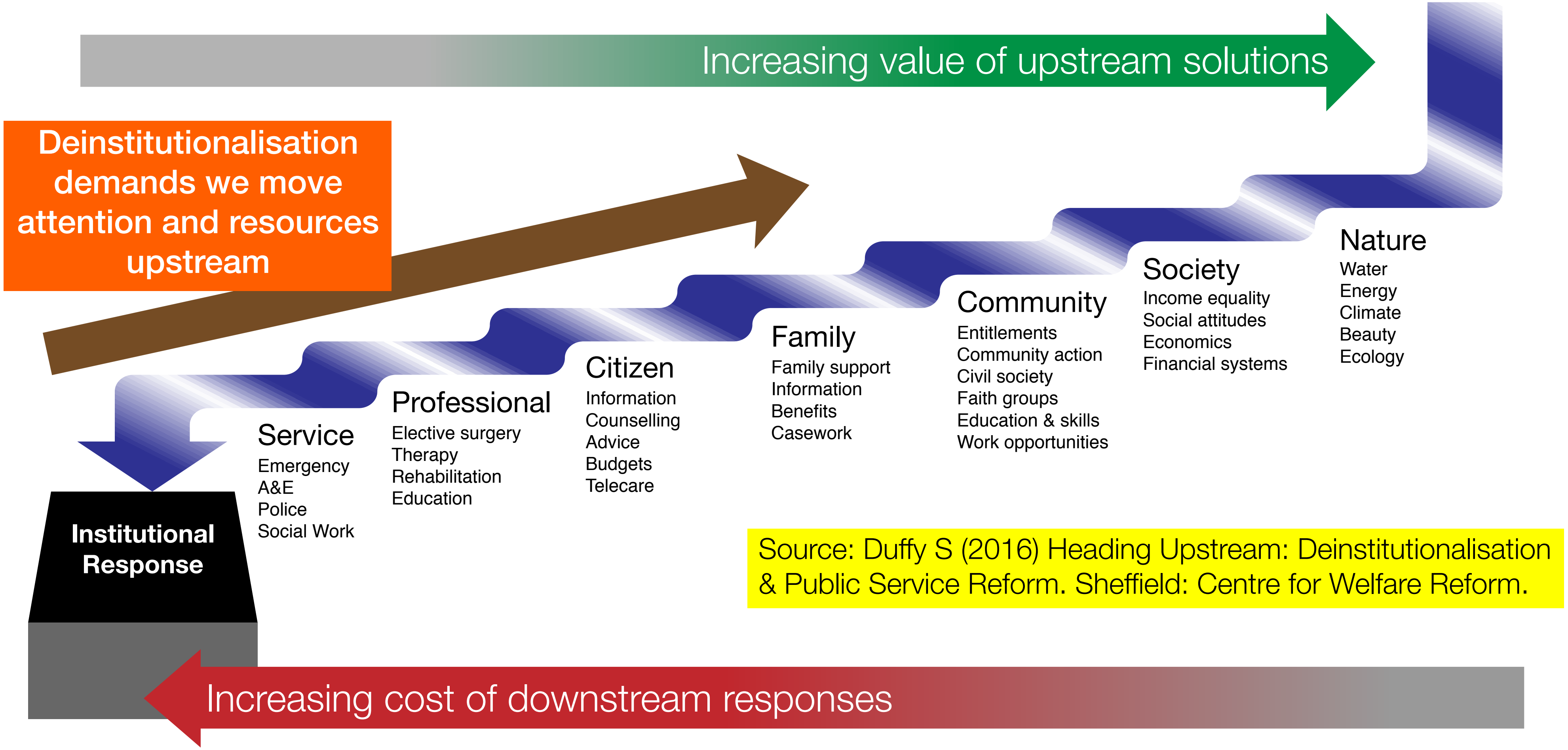
- **NHS psychiatrist will only be working for the state, and there is less of a financial incentive to deem people as not ready for discharge.**
- **People are more likely to be placed locally, which makes family contact and discharge easier.**
- **There will be no more private investment into institutions and no more public money lost to those investors.**

Closing the private institutions **first** is the best policy.

Furthermore, we must stop psychiatrists in private hospitals from determining whether someone is ready for discharge. Instead we must put all such decisions totally in the control of professionals wholly employed by the NHS.

Also - it is quite possible to **forbid sending of children into institutional placements**. This was an important principle in the early days of deinstitutionalisation. Forbidding the institutionalisation of children sends a strong message that we are serious about our goals, and given the numbers this ban is utterly achievable.

In addition we must **end regional funding for institutional placements**. All regional funding must be distributed back to local areas. This will end the system temptation for regionally funded placements. Instead local areas will be benefit when they bring people home and will be less tempted to allow people to leave home. Currently all children placements are funded regionally and the possibility of accessing additional regional funding sends entirely the wrong message to the system (NHS England, 2018).



Increasing value of upstream solutions

Deinstitutionalisation demands we move attention and resources upstream

Institutional Response

Service
Emergency
A&E
Police
Social Work

Professional
Elective surgery
Therapy
Rehabilitation
Education

Citizen
Information
Counselling
Advice
Budgets
Telecare

Family
Family support
Information
Benefits
Casework

Community
Entitlements
Community action
Civil society
Faith groups
Education & skills
Work opportunities

Society
Income equality
Social attitudes
Economics
Financial systems

Nature
Water
Energy
Climate
Beauty
Ecology

Increasing cost of downstream responses

Source: Duffy S (2016) Heading Upstream: Deinstitutionalisation & Public Service Reform. Sheffield: Centre for Welfare Reform.

10. Reinforce human rights protections

Finally we must demonstrate more clearly that institutionalisation is not a failure in the quality of services, it is a failure in human rights. Going forward we must talk more clearly about false imprisonment, segregation and the crimes committed against people who have been placed in the custody of the state; only then will we make real progress. Instead of talking about 'abuse' we need to be talking about 'crime' and the penalties and punishments for these crimes should be commensurate with their seriousness.

Ideally the whole health and social care system would be properly reformed and the unjust policy of Austerity would come to an end. This would mean not just fixing the problem of properly funding social care, but it would mean redefining the roles of the NHS and local government and moving away from our institutionalised system of 'community care' towards a truly personalised and community-based system.

In particular government needs to work with the disability and family movement to create clearer rights and systems of checks and balances to defend those rights. There has been a long-standing failure to respect the full breadth of human rights - which includes social and economic rights - and to see that basic rights to freedom must have a signifiant impact on how we interpret the role of public services and the welfare state (Hunt, 2017).

The protection of human rights are vital to everyone. It is a mistake to think of human rights as only being necessary *in extremis*. In fact, if we take seriously the human rights principles which are at stake in the case of health and social care system for people with learning difficulties and autism then we will make possible many other positive reforms which will benefit everyone.

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