



Resilience, identity and contribution

The need for a person centred approach to the integration of support to people and communities

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Summary

Integration is seen as a solution to limited and decreasing budgets, inefficient and duplicating systems and as a way of becoming more focused on people.

If it is to succeed then integration must start from the person, not from organisational arrangement.

Any change to how people are supported must be centred on improving the actual, lived experience of those people.

Our life experience, belief, faith, culture, and history shape our identity, that is how we live and what is most important and cherished to each of us.

Wealth and poverty are not simple monetary measures but about all the resources we have or do not have.

Communities can be rich sources of support, interaction and opportunity; public services can have an important role in facilitating and increasing the richness and wealth within local communities.

The three key elements of person centred integration are:

1. **Resilience:** The person, child, family and what they can contribute; their 'real wealth'
2. **Participation:** The community within which the person, child and family live; and the community activities in which they participate.
3. **Support:** The local offer of services and support made available through the local and national statutory sector

A person centred approach to integration means working in a cohesive and concerted way to invest in both the real wealth of local communities and that of its members.

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Making the case

This paper sets out In Control's perspective on *integration*, something which is held to be a major part of the answer to the problems of today's public services. We strongly support integration, but we also have concerns. As the term *integration* is used today, it is frequently a synonym for organisational merger: if we bring organisations together, so the argument goes, it will follow naturally that eligibility is simpler, staff will work together better and more efficiently and the experience for those using services will be improved. We see real dangers in this argument, the main one being that it is a prescription for re-structuring and re-configuration but not for changed thinking or the shift in power that will then empower children, young people, families and adults who need additional support. Too often the 'customer experience' of re-structuring is disruption, confusion and poorer services. True integration must start from the individual and from their specific circumstance. It must draw on aligned processes and budgets and it may end up with mergers, but this is the end-point, not the beginning. Integration must engage with the individual as a person, taking account of their values, beliefs, experiences, their skills, and of their ability to contribute – as well as their needs. It must design support *around them* rather than ask them to contort themselves to fit the mould of services.

We are all the same: we all want a good life and we all care about the things that are important to us and we all have connection with other people around us. But we are also all profoundly different. We are all human beings with a *particular* set of values, beliefs, experiences, skills; and relationships to others – family, friends, workmates, neighbours; as a consequence we each bring a particular set of *demands*. Publicly funded services must work together to add their distinctive contribution in subtly different ways to each of these individual, specific personal situations and 'presentations.' We advocate integration 'up' which begins with the person and *demands* that services work together in order to provide the kind of subtle, sophisticated support solutions that individuals really need rather than integration 'down,' meaning the integration of systems, processes and departments, 'making professionals work together,' and being reliant on fervent *hopes* for a good outcome for the individual.

Integration will not be 'optional' for much longer: the Care Act makes it a requirement of local authorities. Similarly, the Children and Families Act 2014 is premised on much greater integration, particularly across education, health and social care. The only contention appears to be how quick and how deep the changes should go – and crucially about how precisely to bring them about. Our concern is that by not defining the '*how*', the system defaults back to type, that is to *organisational re-structuring*, a path that is very familiar and well-trodden in public services.

In reality, organisationally driven integration is not simple and straightforward even on its own terms, as some of the government's integration pioneers are finding. The much quoted 'Mrs Smith' model in Torbay is now 10 years old. Mrs Smith is a typical older lady who needs a range of health and social care services. Starting from an individual is a great first step: and much of the subsequent action in Torbay has tried to maintain a person-centred focus, but other places seem to have found it difficult to replicate this, one suspects because they are largely preoccupied with organisational or structural solutions, rather than with the person-centred premise, so they have often foundered¹.

The accompanying paper to this, 'Creating an integrated, outcome-focused and family-centred offer'² spells out in some detail how we see the organising principle of *person-centredness* working in practice and in particular around funding. It proposes that we start with the individual, their assessed 'need,' an

¹ <http://www.torbaycaretrust.nhs.uk/aboutus/Pages/TheTorbayModel-MrsSmith.aspx>

² www.in-control.org.uk/childrenspublications

assessment which takes account of assets and connections; and in this way we define the call that *this person* makes on those around them *and where necessary on* the public purse and on different commissioners or deliverers of public service (education, health, social care, housing etc.). The requirement is that these services *must* come together to meet that need. They must integrate.

In July 2013, the Local Government Association (LGA), one of the strongest advocates for faster, deeper integration, said:

“...integration should now be a mainstream activity, not a series of experiments in small areas. The scale and pace of integration across England needs to accelerate dramatically in order to tackle the challenges posed by an ageing population, increasing costs, and reduced resources³.”

Later in 2013, the LGA published a 102-page evidence review, which makes the case, based primarily on ‘the financial benefits of integrated care.’⁴ This paper seeks to set out the challenges and present some of the options that would enable *person centred integration* - that is an approach based on a real partnership between the person, child, family, their community or communities - and the local offer through public funding. This local offer links well with the starting point explained by the LGA - that is of place-based public service, however we see the starting point as the person themselves, with an understanding of how the local offer can be shaped around that individual and their community.

Personalisation, systemic arrangements which enhance individual self-determination, is the driving force of positive change in public services today.

Starting with adult social care support and now gathering pace in children’s services and the NHS we see individuals taking control, exercising choice and finding their voice, often for the first time. We see genuinely person centred solutions springing to life in places where they were previously unknown and where individuals were held back by the fetters of bureaucracy and overcautious ‘service solutions.’

Personalisation is an organising principle around which we can *integrate*.

The challenge is that a personalised approach is still far from the norm in many places. Public statements, procedures and the attitude and approach of some staff and managers have begun to change, but there remains a deeply-held set of beliefs that at the end of the day control over the public purse, over ‘how money is spent’, needs to sit with accountable public officials: hence many authorities prescribe lists of goods and services which can and cannot be purchased with a personal budget. This mind-set is perhaps understandable given the requirement to bear down on budgets, but the way this bearing down has been done has often been unhelpful in the extreme. It would be all too easy in this climate to lose faith, to return to the comfort of top-down solutions which concern systems (relatively easy to fix) rather than individuals (much more difficult), this is the challenge faced by pathfinders and the pioneers, i.e. to retain a focus on the person, child and family and whilst having to redesign services and approaches to commissioning maintain both commitment and focus on being person centred and the need to integrate to improve the lives of people who need support.

³ Local Government Association, 2013, *Rewiring Public Services, Adult Social Care and Health*, available to download at <http://www.local.gov.uk/>

⁴ Local Government Association, 2013, *Integrated Care, Evidence Review*, available at <http://www.local.gov.uk/>

Personalisation has too often been timid in its implementation

Work has focused too much on the system and support needed to allocate resources and to get and manage a personal budget; and not sufficiently on the cultures, the communities and the *identity* of those needing support. To further inform our position we need to review first the learning to date from the past 10 years of watching and trying to influence the implementation of self-directed support; and second to take stock of some of the research about integration in complex systems such as the British public sector: why is it so difficult and what learning is there that we might draw upon?

Lessons from personalisation

Accounts of the success of personalisation are now readily available⁵. Probably the most important testimony to date is the second National Personal Budget survey, based on the POET (Personal Outcomes Evaluation Tool) methodology which seeks to capture and aggregate self-reports of life change⁶.

Rather than rehearsing this material once more, it may be more useful for our purposes here to summarise what we have learnt about what does *not* constitute full reform of public services:

- We have learnt that reform is not primarily about systems and processes. In the early days of our work we concentrated mainly on work with councils to help them switch ‘operating system.’ Our view now is that this was necessary, but was by no means sufficient, and certainly not in situations where the organisational culture or the power balance remained unchanged.
- It is most certainly not just about *financial* or *resource allocation* systems, important though these are. We have seen too many local systems get stuck trying to find the perfect system.
- Nor is it only about *person-centred thinking or planning*. Again, these are important pre-requisites, but in the past too many plans have been no more than pretty wallpaper, with no impact on a person’s life.
- It is not about the *ending of block contracts* or even about *increasing the number of personal budgets*, both important building blocks, but not to be equated with creating a genuinely personalised approach.
- And it is not about agencies *working together* or joining as (for example) ‘the team around the child’: again such arrangements are almost always helpful, but they are neither a panacea nor a guarantor of better outcomes.

All of these changes are *part* of the whole picture in fact. Self-directed support and personal budgets have the potential to provide the central organising principle around which a truly joined up approach (‘joined up’ not only across traditional agencies, but also between agencies and individuals, families, communities) can coalesce. To ignore or downplay the central place of the individual person, child or family in this is to ignore the rationale for ‘public services’ in the first place. Integration, the bringing together of funding and systems to deliver greater efficiency and improve the support offered to individuals cannot be allowed to become a complex flow diagram or systems model which reduces the person to passive flotsam carried through the system. Integration must be integration around the person.

⁵ See for example the Think Local, Act Personal website, <http://www.thinklocalactpersonal.org.uk/>

⁶ Available at www.in-control.org.uk/poet

The potential of integration

There is huge potential in integration where it is shaped by people and where it is truly 'person centred'.

The following story begins to illustrate the challenges.

Introducing Mohamed and his family

Mohammed Aaqil is a Moslem man of Pakistani origin in his late 40s, born and bred in the city of Wolverhampton. He is the father of three teenage daughters, one of whom, Zahera has a rare neurological condition which affects her speech, mobility, her eating and drinking and her mobility. Mohammed used to be a boilermaker in a medium-sized local company, but eight years ago he was laid off and is now a taxi driver; he attends Friday prayers and is well connected to his faith community. He is also a member of his local Labour party. He supports Wolverhampton Wanderers and gets to most home games. He has a wife, Madiha who worked in Tesco for many years and although she still does a few shifts each week she now mainly spends her days at home caring for Zahera. Mohammed also has an elderly mother, Mrs Aaqil in the next street who is increasingly frail. Money is short and Mohammed worries about the future. One of his main worries is about what will happen to Zahera when she can no longer live at home. Currently Zahera attends the local special school, where she receives one-to-one support in the classroom. The family has lots of people around them, friends and members of the extended family, some of whom help a great deal; possibly could help more and in different ways, but the family feel stuck and unsure how to approach or guide people. There is no doubt that they need a steer. They need particularly to think about how mum will be cared for and what the options are for Zahera.

So the family needs help in making some decisions, in coming to terms with their future, both jointly as a unit and individually as they move to new phases. It is critical that these decisions take full account of their culture, their relationships with extended family and friends and their participation in the wider community. They also need to weave in the help of professionals, doctors and nurses who can help manage Zahera's symptoms, speech and language therapists for her communication needs and perhaps the wheelchair service or podiatrists who can help with her mobility. And they need to take account of Mrs Aaqil's increasing frailty, and what she can and cannot expect from her extended family, so perhaps professionals in older people's services and agency workers will be involved too. These professionals are part of the picture and to be effective they need to work together, whether they are employed by the NHS, the local authority or by neither. They also need to work with the community and with the family's 'real wealth.'

Real integration means an equal partnership between the child, the family, the adult and their communities – set alongside offers of support through public funding. Integration, the joining or alignment of processes and funding to deliver greater efficiencies should be much more than a flow diagram or systems model: it becomes instead a way of bringing all the community's resources to bear in different ways around each person and each family.

When we think about an actual person, we think about them in terms of *personal identity*, what makes them tick, who they really are. Mohammed's personal identity is very different from that of a white, 70-year-old British woman, 20 miles away in a Staffordshire village. In the language of person centred planning this is 'what is important to me: what I believe, what I care about, my interactions with others, my

participation in my local community or online communities and the way I want to be supported'. Personal identity is the glue of community: through participation in community life as young people we discover and come to live out what we care about and who we are, and as adults we continue to live, learn and participate. *Community identity*, for example a faith, belief or language is what binds community members together in unifying activity. Through these different forms of identity we come to *contribute*, that is we give back to others around us, to those we care about. In doing this we form relationships which are two-way, we develop a sense of self-worth and personal dignity – and we build a stock of freely given goods within the wider community. This contribution can be made in as wide a variety of ways as there are members of the community (it's personalised) but what is new and (and in many cases still in development) are the tools to channel it: so volunteering schemes, time-banks, shared lives schemes, home-sharing are all helpful in gathering and directing this energy in empowering citizen-directed ways.

The three key elements of person centred integration are:

1. **Resilience: the person, child, family** and what they can contribute.
2. **Participation: the community** within which the person, child and family live; and the communities of whom they are members.
3. **Support: the local offer** of services and support made available through the local and national statutory sector.

We can fit these three elements together in numerous ways. For example, *support* enables a person to *participate* in the life of their local community (by being a good neighbour, a friend or a volunteer perhaps): through a sense of belonging the person's *resilience* is greater, they become stronger and more able to help themselves and others and to provide further *support*.

One thing that is important to Mohammed and his family is their faith and the fact that they belong to a faith *community* within their neighbourhood. Both Mohammed's daughter and mother receive support from that community, and the whole family is sustained and strengthened by it. We sometimes refer to this sustenance as *community wealth*, a means of binding people together around shared beliefs and shared support. The challenge to commissioners and to services is to acknowledge the power and reach of this community wealth; to allow it to work its magic by drawing strength from what matters to people; and to decide when and how to add to it where necessary. The intention then is to build resilience from the ground-up, rather than create dependency from the top-down.

Person centred integration is about supporting community members towards independence, interaction and interdependence and doing so in simple, easily-understood ways that make sense to people.

Three components of person centred integration: the person, child and family: their *real wealth*



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People: family friends, neighbours, colleagues.

Access: access to the world, physical access, accessing information.

Assets: possessions, money, buildings, garden.

Skills and knowledge: abilities.

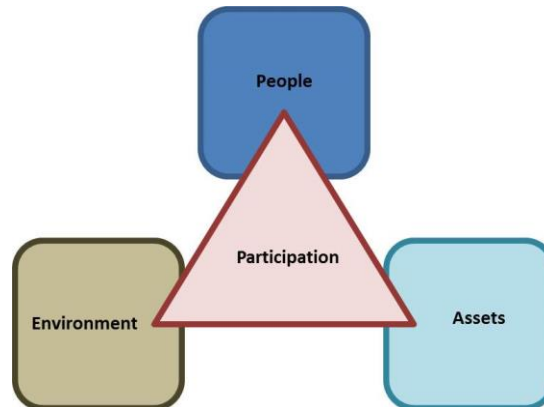
Resilience: faith, belief, love, friendship, company, well-being, family.

A person, child or family all have strengths, resources, abilities which can be invested in and built upon to help sustain these strengths. Similarly many may have gaps in their strengths and abilities; identifying them and then investing in support to help the individual resolve these gaps can support increased resilience, increased strength.

The use of funding and the offer of support is best used where it builds on the strengths of the individual and where it helps fills gaps in the individual's and/or family's own resources. The purpose of integration where it is focused on individual lives is to invest via personal budget or personalised service. The outcome we aim for is to grow resilience and the resources an individual has to call on to live independently, contribute through employment and participation, and when a parent is to provide a safe and healthy home life for their child or children.

The wealth of *communities*

When someone is a true member of a community by definition they are less isolated; generally they are in better communication with others; they feel better about themselves and they are safer. This is true because we know that most communities have a wealth of resources their members can draw on at different times. The diagram below sets this out.



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People: the members of a community.

Environment: the surroundings, rural or urban; the local political environment; attitudes, particularly openness to diversity and difference.

Assets: community buildings, space, and other resources; buildings which are a focus for a community, for example a community centre; or a church or temple or buildings with an activity focus, like a gym or arts centre; the accessibility of these community resources; community budgets; local council tax.

Participation: what unifies, encourages and supports participation; geography, faith, interest, representation.

Participation, a sense of belonging and of membership are key aspects of people's lives, aspects which reflect and reinforce *personal identity*. Identity comes in part from geography (I live in this street, this neighbourhood, this city), but also through membership of diverse communities which may be rooted in faith, health, sport, the natural environment, hobbies, politics, work or volunteering. In reality many of those who seek additional support start from a position of isolation, of being outside of community; an approach to integration which invests in the community, in people, the environment and in community assets will foster a more open and approachable opportunity for people to find a place for themselves.

Community, both formal and informal remains overlooked when identifying sources of support or participation for people. In part this is an issue for commissioners: before considering what 'special services' they need to develop and fund, they are well-advised to begin by asking questions about universal or mainstream services, that is about the people, environment and assets of existing communities: how can these be encouraged to flex to meet support needs? And when thinking about 'integration' we need to start from the resources of local communities: how might these become potential sources of support and how might they develop and grow in ways that are sustainable and inclusive?

The local offer of support, opportunity, activity and participation



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Universal services and the mainstream: leisure centres, university, GP surgeries, A&E departments, apprenticeships, banks and finance services, parks, shops, nurseries, town centres, pubs, cafes, markets, schools, colleges.

Targeted services and support: youth clubs, teenage pregnancy services, Macmillan nurses, special schools, health services commissioned to support a specific diagnosis, school transport, short break services, activity days, summer play schemes.

Social capital and community wealth: an underused source of support for people and one which to date has failed to attract anything other than pilot work around 'place' from commissioners. Work to develop the wealth within communities will need to be taken forward underpinned with genuine co-production – services, communities and people working together.

Choice and control - self-directed support: some people will need more support than is readily available to the mass population. The offer of personal budgets and personalised support/funding fits in to a comprehensive local offer of support and sets out for commissioners what activities they can do in partnership with local people to offer both sources of support and to increase inclusive opportunities in the local mainstream, the use of targeted support and in local communities.

Interaction and interdependence

For integration to work, and to be person centred, then it will succeed by promoting interaction between the person, their community and the local support offer, that is it will seek to value and promote the interdependence between the individual, their community(ies) and what the public purse funds. This is not as 'nebulous' as it might sound. As an example, investment in increased access to local leisure centres means more children, young people and families can use the swimming facilities; through regular attendance friendships can develop, such friendships tackle isolation, build informal support and promote healthy activity.

Clearly defined outcomes which are meaningful to the individual or family will unite resources and hence the way they interact. In this way we will move away from our traditional 'silo-led' approach to *meeting needs* and replace this with an emphasis on *achieving outcomes* (which we can define in a variety of ways; to participate, achieve and enjoy, for example) so that we bring all available resources to bear on the things that people care about and which are shaped by their sense of both personal and community *identity*.

Integration means.....a focus on outcomes and making best use of all resources; real wealth, community wealth and the local offer of support.

Integration means.....identifying the gaps in wealth and tackling through a joined up approach focused on improving life outcomes.

True integration fosters the coming together of resources, in ways that make getting support for individuals and families easy to understand, easy to access and which makes sense in their day-to-day lives. We know it is working if this is what people tell us.

How do commissioners and those leading integration make best use of the funding and services available to them to deliver person centred support to Mohammed and his family; what activity can they undertake which fosters capacity and values and builds upon the willingness of the local community and extended family and how best can they deliver simple, outcomes focused and efficient support to family members who need it, i.e. mum and daughter?

True integration poses some challenges for the government and for local commissioners: how do commissioners evaluate and factor in real wealth and community wealth in ways that people don't experience as exploiting them or asking too much; what is a reasonable contribution from particular communities; and how can public funding enhance and amplify all of this without promoting dependency? How do we work to strengthen and improve each of these elements so that they work in harmony and are mutually reinforcing?

Using the quadrant graphic as an illustration of ‘the local offer of support’ we can attempt to respond to these challenges:



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Integration means.....that commissioning activity will be integrated and will be a partnership of local statutory services, local communities and local people. Such practice will be supported by an integrated approach to funding, ideally from a single budget for each individual.

The underlying challenge is that far from being integrated we are currently spilt; into silos, territories, patches of command and control and a lack of whole system thinking where communities are barely linked to the ‘formal’ support offer. An approach which simply focuses on re-organising this service system will not deliver the improvement in outcomes for individuals which in the end can be the only justification for further disruptive (and expensive) ‘re-organisation’. Personal budgets have enabled many people to take control of their lives and make changes to the ways in which they and their loved ones live; however this development has further to travel if it is to enable all citizens to make real choices and get real control. Personal budgets are a means to an end: that end is empowered citizens in control of their lives. Integration is not simply for those with support needs who need the additional investment of a personal budget; it is about the fundamental relationship between each and every citizen, their communities and the state.

We will meet the challenges we list only if we appreciate that the elements of the system are intimately connected and not independent of each other. Each of us who needs support will draw naturally on our own personal resources; on informal and community resources; *and* on the local offer of support. How we do this will be based on how we each of us, understands and makes sense of the world, our personal identity, both who we are now and who we wish to become in the future – our hopes and dreams; person centred integration grows through appreciating this, through supporting different ways of learning, living and achieving and making best use of the interdependency of the individual, the community and the publicly funded local offer.

Towards person centred integration: some key questions for commissioners:

- What can we do to build greater community wealth and more inclusive and welcoming communities? For example, can we provide community budgets and promote local decision making about how these are used? What is the contribution of different agencies to this?
- What activities can we undertake that invests in the universal offer to our local population? For example, how can we make mainstream services more accessible for everyone including those with complicated support needs? What is the contribution of different agencies to this?
- What targeted services do we have to influence and in what ways in order to support different groups of people? Is this the best way of using our limited resources - and how do we know?
- How do we best engage with colleagues from other agencies to discuss these issues and align what we do? How do we include local people in these discussions so they are co-produced? How in particular do we make staff roles across agencies more flexible to avoid duplication and confusion?
- How do we encourage people using a personal budget to make best use of both *community wealth*, the support from their local communities and their own resources, their *real wealth*? How do we make personal budgets from different sources seamless to the person using them?
- And how can we use the organisation's tools at our disposal (community development resources, Joint Strategic Needs Assessments, market shaping tools, Health and Wellbeing Boards etc.) to help to achieve these things? How can we ensure all agencies buy into these approaches?

Our approach to integration is strengths-based. Planning and support are individual and family centred and build upon the resilience and contribution of those closest, those who care most about the individual. The first source of support then is the family and those in the person's circle of intimacy; the second is the local community; and the third is support from public funding.

We now need to go to the next level in making personalisation work. This means disposing of the complex systems onto which we have superimposed personalisation and personal budgets. The short history of personalisation provides great learning as we push towards integration; we have seen an approach that started out as a simple and common sense solution to the high cost, poor outcomes and disparate approaches to supporting people descend in some cases into complexity, turf wars and stagnation. The challenges are complex but person centred integration is a simple response, a basis to help us do things better, together.

Each of us who needs support will draw naturally on our own personal resources; on informal and community resources; *and* on the local offer of support.

What would it look like if things were integrated in a person centred way for Mohammed and his family?

If we stood back and thought through the approach we have set out what would it mean in reality? For a family who have shown great strengths in supporting a profoundly disabled daughter and an increasingly frail mother. A family who are part of a caring faith community, who speak their language and value many of the things which Mohammed and Madiha see as central to their identity: a family and community with great wealth.

This would mean that commissioners coming to value the resources within the faith community, in this example the Muslim community: it could just as easily be a Hindu or Christian community, a geographically isolated community like the Scilly Isles or Outer Hebrides, a market town or a vibrant and active multi-cultural part of a large city. Decisions could be taken to invest in community building, utilising asset-based models such as Local Area Co-ordination, Keyring¹/Neighbourhood Networks¹ or Time-banks/LETS¹. Such investment could act both to develop and strengthen links with the local community, tackling the isolation experienced by many carers and people receiving support and giving a voice to the local community in local decision making to do what matters most to them, perhaps improving local transport or enhancing the accessibility of leisure services or community centres or providing better on-line information in languages other than English.

We also need to think through the efficient use of *people resources*. In part this would mean identifying the most appropriate worker for the *whole situation* and linking them to the family, rather than having one worker for the child and for the adult. This is a real challenge for services, which have become increasingly split and increasingly specialist, but it is critical. A focus on promoting family capacity and resilience would centre on a healthy home life, the sleep and rest all family members need, access to additional funding whether from local agencies or eligible benefits / tax credits, promoting healthy living. Strengthening the family in these joined-up ways is a start to ensuring that Zahera and Mrs Aaqil get what they both need. It would help the family itself to build and sustain the strength and capacity to support them; it would ensure they looked first to their community for further support; and finally it would seek to ensure that any additional support fits around their identity and wraps around their strengths.

Conclusion

Our work with children, families and adults of all ages has shown that many of the elements of person centred integration are already in existence in parts of the country: Local Area Co-ordination, strength-based social work, family group conferencing, think family, personal budgets, community budget holding and genuine joint commissioning are all examples. But we rarely find examples where this is viewed as a whole system, where investment is co-ordinated and centred on individuals and families. This flaw is the result of a top-down approach to service design and delivery. Person centred integration is a simple means to think through and simplify the whole system. It is rooted *in personal identity*, how we each define ourselves and find meaning; it builds upon personal strengths, our assets or *real wealth*; it adds the opportunities which our communities present, what we call *community wealth*; and it sets public services the challenge of building on this basis through using increasingly scarce resources in ways which are cohesive and *integrated*.

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