Redesigning the front end of social care

There are many aspects to the social care system. This paper focuses on the ‘front end’ of the system – what happens when we first encounter social care. It looks at the experiences of assessments and discussions about eligibility and access to services. It asks what those processes do to an individual’s independence and to their relationships with their family and community, and whether the White Paper is an opportunity to create a system which feels more like a partnership, and less like a battle.

This paper is intended as a starting point for debate. We expect to develop the ideas and solutions in future years.

The challenges

At present, people’s experience of social care can be characterised by:

1. Eligibility and needs assessment: “Are you vulnerable and needy enough for us to talk to you?”
2. Up-front means-testing: “Are you poor enough for us to offer you something?”
3. Complex jargon, assessments and resource allocation systems: “You need a professional guide to negotiate our care pathway.”
4. Dependence: “We can help you as long as you have critical needs and your family refuses to help.”
5. Medicalisation and labelling: “Our experts have decided upon your needs and category.”

All of this feels, for many people, as if the most important question for professionals is: “Are you in, or out, of our system?” Professionals, meanwhile, are caught between conflicting roles: gatekeeper, enabler, rationer, advocate.

Being ‘out’ of the system can mean:

- No service offered until your needs increase and your resilience drops to crisis point
- No help to plan for future care needs or to consider what informal resources might be in your community
- A battle to challenge assessments, with a focus on proving needs or risks are more acute than they have been recognised to be
- Having to refuse much-needed help from family and elsewhere, in order to qualify for services
Edith is 87 and needs increasing help with everyday tasks around the home and to live comfortably. Her family contacted their local social services but discovered Edith wasn’t eligible for support. Feeling unable to cope with the level of support that Edith required, and worried about her deteriorating health and confidence, her family started to look into challenging the local authority and into residential care.

After being put in contact with a local self-directed support advocate, the family were supported to plan for Edith. They identified the help Edith needed and what informal support existed through family members, friends and neighbours. By doing this the family discovered that with the support of others, they were able to meet Edith’s needs enabling her to stay at home, ‘out of the system’ and out of residential care.

But being ‘in’ the system can also have negative impacts:

- Needing to maintain eligibility and therefore dependence
- Ceding power and control to professionals and systems
- Having to resign yourself to maintenance from services which promote dependence
- A continuing focus on service solutions
- Stigma
- Isolation from informal sources of support

At 19, Andrew was diagnosed with drug induced psychosis. Reluctant to accept social care intervention, Andrew decided to manage his addiction on his own. He did this by moving out of his community and living remotely in a tent where he had no access to drugs. At 21, he had a road traffic accident resulting in a severely broken leg. Again, Andrew was reluctant to accept traditional ‘service solution’ help and his lack of cooperation with hospital staff resulted in further damage to his leg. Due to his mental health needs and disability, Andrew ended up dependent on the system, receiving benefits and disability living allowance and this continued for 20 years.

In 2005, his family became aware of personal budgets and began to explore how one could work for him. This process along with planning his support enabled his family to explore his capacities rather than his disabilities. This led to the revelation that Andrew had been refusing treatment all this time because he was afraid he would be given morphine which would re-start his addiction. This was soon resolved and Andrew agreed to an operation with alternative pain management.

The operation was a success and Andrew used some of his personal budget to support him to get a job. He is now in full time employment, he no longer receives benefits and he has regained his pride and confidence.
The rationale for the current system design is:

Expensive and limited professional-led services are the only way of meeting most social care needs. Potential need is vast, so the state needs to gate-keep and ration services, keeping people out of the system as long as possible, allocating the minimum support possible and charging wherever possible.

Beneath that rationale, lurk ideas which can be traced back to the Poor Law: government services are necessary as a safety net for the (deserving) poor; they must be protected from those who wish to ‘game’ the system. This fundamental lack of respect and trust between state and citizen has proved the single biggest barrier to implementing personalisation, which is a concept based upon trust and empowerment.

That rationale is not only morally, but factually faulty - services are not the only way. Most people with social care needs are not eligible for support - they support themselves. Many social care needs, such as isolation or social exclusion, are not ‘fixable’ with a service. Family carers’ support is worth more (over £100bn per year) than state services are. So the case for a system based on rationing and gate-keeping access to expensive crisis services is inherently flawed. Delays in access to support create a backlog of unmet need, leading to costly problems and people having fewer chances to build their own resources and solutions sustainably.

Not always obvious within the system is a considerable amount of spending upon services which attempt to inform, advice and guide people, including those who do not have acute support needs. But these interventions are offered within the context of a limited understanding of the options which might be available to people. They tend to help people navigate complexity, rather than seeking to create simplicity:

- Information services, written resources and websites
- Advisors, navigators
- Brokers
- Advocates

There are also attempts to help people to co-design and contribute to their own solutions:

- User-led organisations and pockets of user-led commissioning
- Peer support initiatives
- Support to access a personal budget and to design a support package
- Pockets of community development work

However, these ‘asset-based’ approaches are a small part of a deficit-obsessed system and lack widespread power and legitimacy. A lot of user-led work is commissioned to contribute to consultation upon service-led agendas. Discussions about a good life and personalised support remain reserved for those with personal budgets, ie those with the highest needs. Those discussions can have an often unhealthy focus upon negotiations around eligibility and the size of an allocation of money.
The solutions

Alternative approaches to helping people to meet their support needs and live a good life have been demonstrated successfully for decades. But those demonstrations have tended to be small-scale and fragmented, characterised by pilots and initiatives, rather than whole system redesign. The need for the latter has never been more pressing and several factors have combined to make real change possible:

- A better-informed and less deferential public now has growing expectations of the quality of services
- A number of linked resources have become established and are well connected with each other. They are all based on seeing people as assets not problems and they believe in citizen leadership and the value of non service solutions
- There is growing recognition that what matters is not a person’s label or diagnosis, but the combined impact of health conditions, social problems, low expectations and communities that aren’t inclusive
- A number of areas are commissioning for whole-system change
- The unaffordability of the current system and the failure of current cost-limiting approaches is now inescapable
- Personalisation is embedded as an approach and the government is committed to a White Paper which has citizen leadership, prevention and a focus upon non-state solutions at its heart

Nick, 31 has severe epilepsy and needs 24-hour support. In 2000, anxious about Nick’s future after leaving college, his mum Carolyn took part in a ‘Partners in Policymaking’ course. Partners in Policymaking is a suite of family leadership courses aimed at building a network of well informed and connected people who can work in partnership with local authorities to effect positive change.

After attending the course, Carolyn was inspired to secure the best possible life for Nick. She started to look at things from a different perspective and to focus what Nick could do, for example his gifts and talents, rather than what he couldn’t do.

Since he was 10, Nick has always demonstrated a real passion for road signs and would constantly point out abandoned ones when he was out. This developed into Nick volunteering in his local community by collecting the abandoned signs. Recognising his unique gift and obvious interest Carolyn encouraged him, and with the support of his personal assistants, Nick made contact with his local authority and started enquiring about what happened to the abandoned signs. He discovered where they were sent and was invited to spend a day there. Nick made a lasting impression and he was invited to volunteer at the recycling centre. After a while, the company was so pleased with the work he was carrying out he was given a paid position and he has recently achieved an NVQ in storage and warehousing. He continues to volunteer within his local community recycling the signs.

Recognising and encouraging Nick’s talent, rather than focusing on his disability has resulted in him gaining paid for work and being able to make a real contribution to his local community.
There are changes which can be made (and in some areas, are being made) at a local level, within the limitations of the current legislative framework. There are others which require a new framework.

Local areas can:

- Offer planning support to a wider group of people, not just those in crisis
- Integrate community development into their offer to people with social care needs
- Adopt ways of helping citizens to take real commissioning control of pooled resources
- Tackle deep-rooted problems such as stigma, exclusion and prejudice
- Treat families and carers as expert partners, offering a much wider range of support, back-up and breaks

But whole-system transformation will remain a challenge as long as legal duties remain exclusively focused upon the need to provide crisis services and whole-population, early intervention and citizen empowerment approaches remain discretionary and seen as peripheral or ‘luxury’ spends. The ‘cliff edge’ between being ‘in’ and ‘out’ of the system, and the associated stigma and creation of dependence, is embedded in the current deficit-assessment system.

**In Control** has developed a Community Fund Holding model, in which decisions can be devolved to communities in ways that bring real choice and control closer to people, enabling local communities to make the best use of their assets: the people, skills and knowledge that already exists within that community. Allowing local authorities to:
- Stimulate a community contribution towards shared public goals
- Create a new alliance and collaborative partnership with communities
- Stimulate innovation and creative community-owned action

Leeds Council has seconded social workers into three of its 39 Neighbourhood Networks, led by older people and is working with the Stamford Forum to bring personal budget holders and these grassroots community groups together to plan more cost-effective services which can operate more effectively through being embedded in genuinely inclusive communities.

Derby Council is introducing Local Area Coordination, in which local area coordinators have an open door, access to small amounts of money and remit to help people find non-service ways of living a good life, with links to other agencies when services are the only option.

Walsall Council has started to develop a Community Hub in which community social workers with other social care colleagues are working closely with hospital and community health professionals to develop links with a range of community associations, initiatives and voluntary sector resources to enable people who have been discharged from hospital or are isolated at home, to access a range of activities and informal networks across the community. This has led to more effective and innovative support planning that moves away from a reliance upon expensive, traditional services provided by the council, to a mechanism by which people access a whole range of community resources that promotes greater personal independence, develops confidence, informal networking, broader community inclusion, reduced isolation and improved health and well being.
So we recommend that government creates a very different ‘front door’ to the system. It should:

- Create a duty upon each area to have in place open-access planning and navigation support for a wide range of adults, with referrals always triggered by life events which indicate an increase in risk. This would be commissioned using existing resources, with current fragmented and non-strategic spending upon information, advice, advocacy, user voice and brokerage being consolidated into a coherent early intervention commissioning strategy
- Create an expectation that every area cedes control of a percentage of its budget to citizen groups which include people who use services
- Replace current deficit-focused community care assessment processes, with an assessment or impact model which more robustly assesses risk and triggers access to planning support at an early stage
- Ensure through workforce training and other means that community development and citizen empowerment is embedded in future social work practice
When coming into contact with the social care system, whatever our level of need, we should feel:

- I can have a conversation about life planning easily as early as I wish
- Early conversations focus upon ways in which I can draw upon and develop my own skills, resources and informal support networks, not upon services
- Where non-service solutions do not exist in my area, a community development practitioner is there to help me or others to develop them
- I can access support without feeling like I have to be ‘in’ the system, nor defined by a label
- Assessments are viewed first and foremost as an aid to planning solutions and avoiding future dependency. They focus upon risks and potential solutions, not just my current level of need
- I can access varying levels of advice, some of it available to all, but also expert advice around specific challenges or services when I need it, independently of the funder of services
- Services - and the associated gate-keeping – will be something I encounter only when my needs are more acute or when I have planned for it in advance
- If I access increasing levels of support, I nevertheless remain feeling in control, able to construct my own solutions and valued for my gifts, skills and contributions to other people and my neighbourhood
- Throughout my experience of contact with the care and support system, I remain in control of the information I help to create about my needs and solutions, and able to give or withhold access to professionals with whom I come into contact
- Groups and events which help shape services and my local area feel easy to understand and to take part in
- I understand my responsibilities and the tasks or risks that I am being asked to share

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