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Rising to the Challenge: Independent Living and People with Learning Disabilities

2015



Thanks to Certitude for allowing us to use their 25th birthday illustration.

ILLUSTRATION: JAKE MEYER

Independent Living is Freedom

In this year, the 800th anniversary year of the Magna Carta, People First England's Gary Bourlet and Kaliya Franklin proposed a new Magna Carta for people with learning disabilities based on the freedoms set out in the UN Convention on the Rights of Persons with Disabilities.

They think that freedom would be: *a world where you could wake up in a comfortable home and go to work being safe and valued.*

There would be no inequality or discrimination. There would be the right to sufficient financial support to feed, house and clothe

yourself and your family. You could make your own choices about where you want to live and what support, if any, you would need. There would be free access to transport and free medical care. Education would be free and available for all. People would be free to love and befriend as they choose.

These basic freedoms which most citizens of the UK take for granted. But in 2015 the 1.5 million adults with a learning disability are frequently blamed, targeted and forbidden these freedoms. This is our challenge!

Extract from A Magna Carta for learning disabled people, Open Democracy 2015.



Rising to the Challenge

My work with people with learning disabilities started 25 years ago, with two of our members, CMG and Certitude, getting people out of Leavesden Hospital in Hertfordshire.

Those who had been institutionalised; professionals, families and people themselves did not believe it was possible for people to live ordinary lives in their communities. 25 years later people supported by good organisations have proved them wrong. We thought we had won

this battle but here we are again in 2015, fighting to get people out of modern day hospitals. It shouldn't be like this.

There are no doubts that the current economic climate poses a threat but what we also see, often where there is plenty of money, is poor care, neglect and

abuse. It doesn't cost anything to listen to what people want, to respect people and their families and to focus our organisations around the people we serve. We can spend the money we have in the system much better and we should not be spending what we have on poor care.

People with learning disabilities, their families and the organisations that support them, are facing some of the biggest challenges ever getting the support they need to live good lives in their communities. Despite these challenges, we still see really good support, really good housing and people

with learning disabilities leading ordinary and rich lives. I feel proud to work with some of our members, providers and commissioners, who get this and show us how it can be done.

These unprecedented challenges require us to do things differently, so this year People First England and H&SA members are coming together as people, families and organisations so that we are stronger. We need a way to not only challenge the wrongs but to actually do something about them, together. We look forward to rising to this challenge with you.

Alicia Wood, CEO H&SA.

Affordable housing and affordable support

Affordable housing and affordable support are the two 'stand out' challenges for providers wanting to deliver supported living options.



Affordable housing is a national problem. It will be one of the most significant barriers to the expansion of supported living and there is no obvious end in sight. Not everyone with a

learning disability is poor, but the vast majority of people with a learning disability live below the average personal income level. At a stroke this rules out buying a home or renting from some private landlords. People with a learning disability are competing with everyone else who does not have enough income to buy a home or afford high private rents for the decreasing pool of affordable social housing.

Most providers are looking at ways that they can raise capital so that they can secure housing. This includes, for example: using their own capital reserves, borrowing money in various ways, and/or getting someone else to invest in property that can then be

used to create supported living options. Housing Associations with their declining rent levels will have less money to spend on development and this will mean less social housing for everyone who needs it including people with a learning disability.

Affordable support is really about what the state is willing to spend on people with a learning disability to support their independence. The story here is more complex. People with a learning disability in receipt of services funded by local authorities have for the most part seen substantially less reductions in support income than any other group - especially older people.

Having said this, as the Government pushes ahead with its goal of significantly lower public spending and lower taxes the resources for the state to pay for support will decline. This will mean that the level of support available will also fall and some people will no longer get the chance to experience a more independent life as a result.

There are no cure-alls for these challenges but a need to think differently about how they are addressed. At the last H&SA annual conference I said in terms of supported living that you could not rely on the state.

Solutions will be about compromise, opportunism and partnership but also about stepping outside the learning disability bunker and seeing what is happening in the wider world of social care.

If we were talking about older people then we would be talking about people making provision for their old age. We will need to start thinking about the idea of families taking more responsibility, specifically financial responsibility, if more people with a learning disability are to enjoy an independent life. This flies in the face of what many people have grown to expect, but whether right or wrong, in the current environment the question will be asked why is it that we expect people to make provision for their old age which is no less inevitable than the ongoing support needs of a person with a learning disability.

For the foreseeable future the state will continue to shoulder the largest proportion of cost for the support of people with a learning disability but without additional funds the 'state offer' will have to become poorer, less person centred and less effective.

Tom Noon, Chairman Cordis Bright
www.cordisbright.co.uk



An independently supported no life

Rich and I were sitting outside a café in Tenerife in baking sunshine last summer when I suddenly said to Rich ‘Look! Look at that.’

‘What?’ said Rich, ‘I dunno what you’re looking at’.

‘Those three people over there... look at them.’

‘What?’

‘When do you ever see people interacting like that in the UK?’

There were three young men. One was a wheelchair user and one apparently non-verbal. They were walking along together and laughing in a kind of jiggly group. Having fun.

We live on the outskirts of a city with a lot of independent

supported living houses (I can’t call them homes) in our neighbourhood. Every so often I see people in twos or threes. A typically grim faced carer striding ahead with one or two people following. There is no interaction and I can’t say I have ever seen any glimpse of joy or enjoyment. More often a low level sense of anxiety.

I can’t help thinking that jargon has got in the way when it comes to learning disabled adults’ lives. All this talk about ‘independent living’ has led to a group of people’s lives being

viewed through a particular lens. One which, too often, strips away any ingredients necessary for happy, engaged, involved community living; love, care, companionship, reciprocity, activity and fun.

The idea of ‘independent living’ is constrained by budgets and resources, by commissioning decisions, the quality of the care providers and the staff they employ. Each person involved in the provision of ‘independent living’, from the top down, are themselves influenced by numerous factors including; what they actually think about learning disabled people, their job satisfaction and salaries, the constraints they are under in their working lives, the support they receive in their workplace, their personal lives, how they feel on a daily basis and so on. The person who the independently

supported life is being done to is powerless. Their families often excluded from real engagement in their lives.

In 2014 there was a bit of a refreshing breeze with the development of the crowdsourced Private Members Bill, the #LBBill, and Norman Lamb stepping up and producing a Green Paper – No Voice Unheard, No Rights Ignored - with proposals to introduce legislative change to strengthen the rights of learning disabled people.

The government has just kicked these proposals in some very long grass. I suspect this means too many people will continue to lead independently supported no lives for some time. What are we going to do about this?

Dr. Sara Ryan Senior research lead, University of Oxford.



Can we afford for people with learning disabilities to live independently?

What are the prospects for everyone with learning disabilities to live independently?

By living independently, I don’t mean necessarily living on your own or the myth of ‘standing on your own two feet’ without any help or support from other people – we all rely on help or support every day, even if we don’t notice (or say thank you as much as we should). I mean people with learning disabilities having the same freedom to be in control of how they live their life as anyone, including having the help and support you need to exercise this control.

We know that some people with learning disabilities in England are disappearing from ‘official statistics’ and not getting support from education or

social services. We know that the support that people with learning disabilities do get and the current benefits system often don’t help people to live independent lives, instead trapping people in a life of poverty, isolation, boredom, everyday segregation and an early death.

Although there have been big cuts to funding for support, the state is still spending a lot of money on supporting people with learning disabilities. Why is so much of this money being spent in ways that don’t help people to live independently? Why is the system stacked against people with learning disabilities working and why,

when they do, rather than being paid for their labour people all too often have to pay for the privilege of engaging in a ‘therapeutic work experience programme’? And from the point of view of a person with learning disabilities, how much of this money do they see or have control over, and how much swirls around people’s heads and directly into the pockets of landlords and service providers?

There is an idea around that the state can’t afford for people with learning disabilities to live independently, and instead the state should focus on withdrawing to provide ‘protection’ for the ‘most vulnerable’. This is the falsest of false economies. More

people with learning disabilities will turn up in prisons, accident and emergency and other hospital services and zombie institutions. And, shamefully, we will all be living in a society that systematically denies a huge group of people the fundamental human rights and support which many of us take for granted without even noticing.

Finally, who are ‘we’? We are everyone, people with learning disabilities and people without learning disabilities together. Can we afford for people with learning disabilities to live independently? We can’t afford for people not to.

Professor Chris Hatton
Lancaster University.



Families are key to making independent living a reality

Think back to when you first moved out of home. Did your family help you decide where to move to and help you to set up your first utility bills? Did you call them the first time there was a power cut, or at times when you missed seeing them daily? Now you live independently (and probably have done for some time!), do you still have contact with your family?

Like anybody else, many people with learning disabilities want to stay in touch and be supported by their families when they move out of home. Support staff come and go; families are always there. Family carers hold a wealth of knowledge and history about their relative and usually know best how to communicate with them. Family carers know the difference between “yeah” and “yesss”, and the meaning of certain body movements.

The Care Act gives family carers stronger legal rights to involvement in their relative’s care and support, even if their relative no longer lives with them. This new law also strengthens the right to support for family

carers themselves. Family carers are seen as equal partners in care and support for the first time in law.

Since the implementation of the Care Act in April this year, our one-to-one support has highlighted a lack of Care Act training for frontline professionals, especially in the area of the rights of family carers. In many parts of England the law is not being followed correctly, resulting in devastating effects on the lives of people with learning disabilities and their family carers. Needs are not properly recognised, resulting in reductions of the support that enables people to live their lives. Family carers will stand in for the loss of support at a

moment’s notice, often ignoring their own needs. They help their relative understand the changes imposed on them, whilst trying everything they can to get the right support reinstated.

Through our support, workshops and information services, Hft’s Family Carer Support Service has empowered families to challenge poor practice and get the right support for their relatives to live independently. By supporting them to speak up and voice their legal rights, family carers are included and listened to. We welcome stronger rights for people and their family carers in law, but feel strongly that better training is needed for frontline professionals, particularly local authority assessors.

The Family Carer Support Service is running workshops across England for family carers. The workshops give families the information and confidence they need to get the right support for themselves and their relative with learning disabilities. We support family carers and develop resources on a wide range of issues; for information or support, please call us on 0808 801 0448 (free, even from mobiles!) and visit www.hft.org.uk/familycarersupport

Rhianon Gale, HFT Family Carer Support Manager



Hft is a national charity supporting people with learning disabilities.

We constantly look for innovative and creative ways to support people with complex needs or challenging behaviours. We use specialist skilled staff and the latest developments in personalised technology to transform care, achieving the best possible outcomes for the people we support.

During the conference, Rhianon Gale from our Family Carer Support Service (a free, national service for carers who have a relative with a learning disability) will be delivering a workshop on using the Care Act to make independent living a reality, alongside Barrister Steve Broach.

For more information on Hft and the services we provide, visit www.hft.org.uk

Transforming outcomes for people with complex needs and challenging behaviour



BIG THANKS to the sponsors of our 2015 Annual Conference, **AJGallagher**, **Certitude** and **HFT**. Their sponsorship enables us to give out free places to people with learning disabilities and families.

Rising to the Challenge

Independent Living and People with Learning Disabilities.

H&SA

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Article 19 - A European Perspective

In the EU large numbers of people with disabilities continue to be placed in long-stay residential care and this is often for life (ENIL-ECCL, 2014). In addition, many disabled people who live with their families “are also excluded from society because of the lack of the necessary support to enable them to participate in the community” (ECCL, 2009).



Forced institutionalisation is a particular issue in Central and Eastern Europe (CEE). Despite the widespread view that the institutionalisation of disabled people can be a serious human rights violation, as well as being an unacceptable form of ‘care’ in the modern age, the “*inappropriate and unjustified institutionalisation of people with disabilities remains prevalent across CEE*” (Mansell J, Knapp M, Beadle-Brown J and Beecham, J, 2007). The Open Society Mental Health Initiative (2012) argues that a primary reason for this is the “*severe lack of support in local communities that would enable them to live in their own homes*”.

Other reports highlight “*the appalling living conditions in some institutions and widespread human rights abuses such as the use of physical restraints, sexual and physical abuse by the staff and other residents, inadequate food, heating and clothing*” (ECCL, 2009).

Common factors marking institutional care by the United Nations High Commission for Human Rights (UNHCHR) are the removal of personal possessions, rigid routines that ignore personal preferences or needs, and with residents having little or no contact with people outside the institution.

HOW DIFFERENT COUNTRIES COMPARE

Institutional care varies significantly in terms of scale and cost between European countries. ENIL (2014) noted the following average costs in institutional/residential care in the 8 countries of the study.

In Belgium the average cost of institutional/residential care is 60,000 EUR. In Bulgaria: 3,500 EUR. In the UK: 31,200 EUR. In France: 91,000 EUR. In Iceland: 50,000 EUR. In Italy: 48,000 EUR. In Slovenia: 16,000. In Sweden: 66,000 EUR. In all 8 countries in

the study, funding is normally tied to the institution rather than the person. People with extensive support needs do not generally leave the institutional/residential care setting. In most countries, persons with disabilities can (in theory) choose between residential care and personal assistance. However, in reality there are many barriers to this. In countries where personal assistance is legislated for, such as Sweden and England, authorities have reduced the funding for personal budgets and, as a result, the eligibility criteria have been restricted (ENIL, 2014).

In Mansell et al’s report (2007), a comparison was undertaken between Italy, England and Germany. The most striking characteristic of the process of service development in the three

CONCLUSION

Despite the fact that, according to the EASPD (2015) “*inclusive societies, in which persons with disabilities fully participate and contribute to the economic, social, political and cultural life, are more cost-effective in the long term*”, the general conclusion is that significantly more needs to be done to make Article 19 a reality. This is the case not just in the UK, but across Europe.

According to ENIL (2014) “*independent living is a relatively new concept in many countries (where it exists at all), there are as yet no cost-effectiveness analyses of Independent Living supports over long-term*”. It is also difficult

IN MOST COUNTRIES, PERSONS WITH DISABILITIES CAN (IN THEORY) CHOOSE BETWEEN RESIDENTIAL CARE AND PERSONAL ASSISTANCE. HOWEVER, IN REALITY THERE ARE MANY BARRIERS TO THIS.

countries was “*the importance of coordination of different agencies involved in the transition process. The number of agencies involved, their geographical spread and the involvement of different tiers of government all make good coordination essential*”

“*The difference in pace between Germany on the one hand and England and Italy on the other seems to have been influenced by the depth of dissatisfaction among decision-makers with institutions. In both Italy and England, the vision of alternatives and the revelation of very poor conditions in institutions was clearly influential in the transition process*”.

to quantify all the benefits of Independent Living. In Europe, public investment decisions should be guided by criteria based on human rights, rather than what may or may not be cheaper. Some research even takes this a step further: “*If the money currently spent on institutional placements was invested in local community-based services, standards would improve, there would be far less risk of abuse, and costs would fall*”.

Kate Newrick,
Business Manager, H&SA
The full article and references:
www.bit.ly/1HG8h5d

United Nations Convention on the Rights of Persons with Disabilities

Purpose of the Convention: To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.



UNCRPD Convention Rights

ARTICLE 5 Equality before the law and non-discrimination.

ARTICLE 8 Right to have State Parties raise awareness, combat prejudices and foster respect for the rights and dignity of persons with disabilities

ARTICLE 9 Equal access to the physical environment, transportation, information and communications

ARTICLE 10 Right to life

ARTICLE 12 Right to equal recognition before the law and legal capacity on an equal basis with others

ARTICLE 13 Equal access to justice

ARTICLE 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment

ARTICLE 16 Freedom from exploitation, violence and abuse

ARTICLE 17 Right to respect for physical and mental integrity

ARTICLE 18 Freedom of movement and nationality

ARTICLE 19 Right to live and participate in the community

ARTICLE 20 Right to personal mobility through provision of affordable aids equipment, assistive technology and personal support

ARTICLE 21 Freedom of expression and opinion and equal access to information

ARTICLE 22 Respect for privacy, regardless of place of residence or living arrangements

ARTICLE 23 Right to non-discrimination in all matters relating to marriage, family, parenthood, relationships and fertility

ARTICLE 24 Right to education within the general education system, without discrimination

ARTICLE 25 Right to healthcare and early identification and intervention without discrimination

ARTICLE 26 Right to habilitation and rehabilitation services in order to attain and maintain maximum independence

ARTICLE 27 Right to work on an equal basis with others

ARTICLE 28 Right to an adequate standard of living and social protection

ARTICLE 29 Right to participate as equals in political and public life

ARTICLE 30 Right to participation in cultural life, recreation, leisure and sport.



**Independence is about choice and control.
It is not about going it alone.**



We all have the right to decide where we want to live and who we want to live with, regardless of need. Some of us might need a bit of support to make those decisions, but it doesn't mean we are any less entitled to make them.

CHANGE are an international human rights organisation who have worked for the equal rights of people with learning disabilities for the past 23 years. We want to break down the barriers faced by people with learning disabilities and/or Autism and get rid of the stereotypes. Our talented staff are recruited because of their skills and expertise, regardless of their support needs. People with learning disabilities and/or Autism are employed on an equal salary to their non-disabled peers, which reflects their skills and dedication to improving the lives of others.

We create accessible information which is co-developed by our accessible design team and a group of experts with learning disabilities. We also deliver user-led training, grant funded projects and run campaigns – all towards a more inclusive and empowering society for people with learning disabilities.

Independent living and equal status within the community is very important to us at CHANGE. We believe that no matter where you live, who you live with, or what support you need, everyone should have choice and control of their lives. Here, three members of staff and volunteers at CHANGE discuss why being independent is so important to them.



SARAH JAMES
Project Worker

Sarah is 25 and has been living independently for the past two years in her own house, with a support worker three times per week.

When I was living at home with my dad I felt like I could not make my own choices and my dad would do everything for me. He did this as he thought it was easier to do this but I was not really learning to do things for myself which I wanted to do. One day I thought to myself this has to change as I was not happy and was getting angry because my dad was taking over.

I knew I needed help so I went looking for a support worker to help me with this. The first time we met we sat down and she asked me what my future goals were. This was the first time anyone had asked me this and for the first time I felt like I was been listened to and heard. I told her one of my main goals was to be living independently in my own home but I told her I didn't think that I could do this. She was the first person to believe in me that I could do this with her support and she talked me through and got me information on the options available to me she told me it was my choice and to think about what I want. We started bidding on council houses but then they told me to stay at home because I am not a high risk.

I was not happy to do this so I decided to look into private housing. My support worker got me some information on this and I found looking for a house very stressful as no one wanted to rent to be because of my disability.

There was also a lot for paperwork and payments to make and sometimes they didn't explain things in way that I understand.

It took me months to find someone who would rent a house to me and when this did happen the rent was put up and I was made to pay a year's rent in advance as she didn't think I could pay rent because of my disability. It can be overwhelming living by myself sometimes as it was a big change for me to get use to but I feel like I have grown as a person and I am now making my own choices and more independent .

Having independence helps me feel in control of my life and that I am making my own choices and not other people making them for me. I have also learned a lot for new skills e.g. using the washing machine and paying bills, also budgeting.

Having a paid job makes my confidence grow as I am earning my own money and I feel like even though I have a disability I can still earn a good wage on the same pay as someone without a disability which makes me feel proud.

A lot of people don't know what help and support is available out there to get the support they need to live independently and there should be more help and support with helping people move out of home for the first time. As a lot of people feel nervous about this.



KENNETH FLETCHER
Volunteer



After I left home I lived in supported living with three other girls. I didn't enjoy it, the staff didn't understand my needs and I didn't have anyone that was a similar age to me to do things with. I didn't know how to travel independently and so I found myself stuck at home a lot. I am now in another supported living placement with two others, I find it really difficult as I don't get on with my housemate. Just because we both have a learning disability doesn't mean we are right to live with each other. In any supported living placement they just seem to be bothered about filling rooms and not putting people together who are compatible.

At the end of the day it is my home, I should feel comfortable in it. I often feel ill because I am so stressed and I forget to eat. I need support to remind me of things like that and help me be more independent. Everyone should have the right to choose who they live with, people with learning disabilities often don't get that choice, why should it be any different for us?



Independent living is important to me, it can make me a happier person and I can choose what I want to do and when. There's independent living with support and then there is leaving people to cope by themselves. Some people need support to be independent and leaving them without any at all can have the opposite effect. For me it is independent on the support workers terms, if I want to go out or do things, it has to be at a time that suits them not me. If I want to cook a meal I often have to wait for them to fill in paper work before they can help me to cook! Paperwork shouldn't come before the individual's support.

I am planning to move into my own home with support before Christmas. I am on a personal budget so I can choose my own staff and they will all be car drivers so I can do what I want when I want. To be independent I need carers who understand my disability and know me, who let me be independent but help me when I need it. Everyone needs help sometimes to live their lives.



JANE MOODY
Volunteer



I have lived in a care home for 20 years. There are 12 people living in my home. I enjoy living in my home, I have lots of choices. If I want to go out to the pub or Christmas shopping for example, staff are always happy to take me out. We interview for the staff in the home, all of the residents have that choice. People sometimes forget that the care home is my home, it's not an office for paperwork and I want to feel relaxed there.

It's important to me that I have that choice. It's my life, it's not anyone elses. I want to do what makes me happy. As well as working for CHANGE, I teach First Aid, I also write poetry which has been published and I perform my creative writing. It's important to me that I can express my feelings and also help other people, as well as myself, it helps me to have a voice.



It is important that people in care have their voices heard. Commissioners and service providers need to listen to people, rather than filling out forms. It would be really boring if everyone did the same thing. It doesn't matter what a person's needs are, they all have their own interests and they should be listened to and respected, as well making sure their needs are met.

Needs are only part of the person, we have wants too, this is what makes us who we are.

The case for reframing 'independent living'

*'No man is an island,
Entire of itself..'*

No man is an island - John Donne

Two definitions of independence tend to dominate our thinking. One concerns autonomy and self-determination. The other centres on self-sufficiency and self-reliance. It is generally held that the two go hand in hand. This is why it has always been deeply challenging conceptually and practically for many people, including policy makers, to reconcile the idea of drawing on State assistance while 'living independently.'

The independent living movement has long sought to challenge this equation, arguing that what matters is self-governance, not self-sufficiency. Independent living is 'not about doing everything for yourself' but about enjoying the same freedom and choices as everyone else through having control over sufficient support.

Yet it seems an impossibly hard nut to crack. Take for example the opening sentence in the Ministerial foreword to the government's response to the No Voice Unheard, No Right Ignored consultation:

'Our vision of a civilised society is one in which we take more responsibility for ourselves and our neighbours as part of thriving communities working together, and with less dependence on remote bureaucracies.'

Here the concept of independence provides justification for a shrinking state, not a case for an enabling state that lies behind the struggle for independent living. Hence we see progress on 'choice and control' in the Care Act 2014, yet fewer and fewer people can access any support. We see Disability Living Allowance replaced with the Personal Independence Payment, with an explicit policy objective

of decreasing the number of claimants by 600,000 by 2018. Engaged, active and inclusive communities are important and much needed. But they are weakened, not strengthened, by a disengaging, increasingly inactive and excluding government.

Professor Gerard Quinn – one of the authors of the United Nations Convention on the Rights of Persons with Disabilities – has argued that disability rights merely provides proof of a universal truth: that individual freedom relies to a considerable extent on social solidarity. No man or woman is an island.

INDEPENDENT LIVING IS 'NOT ABOUT DOING EVERYTHING FOR YOURSELF' BUT ABOUT ENJOYING THE SAME FREEDOM AND CHOICES AS EVERYONE ELSE THROUGH HAVING CONTROL OVER SUFFICIENT SUPPORT.

Such social solidarity need not be expressed solely via the State. But the task of extending and expanding human freedom does demand a society that prizes values such as universal rights and human welfare and which is serious about tackling social and economic disadvantage.

Yet we seem to live in a society which often prizes individualism over any notion of common goods, which regards social and economic disadvantage to be the result of individual choices rather than structural barriers, and which is less and less willing to commit public resources to social welfare, save to care for 'the most vulnerable.'

Faced with such public attitudes, anti-austerity campaigners are increasingly pleading the vulnerability and intrinsic lack of capabilities of disabled people to shield them from cuts and punitive sanctions regimes. This plays to society's prejudices regarding disabled people as objects of charity and care rather than as equal citizens. It risks undermining efforts to put more power in the hands of disabled

people and to secure recognition of and action on discrimination.

Yet those who have pursued reforms such as direct payments and individual budgets have also risked giving credence to social values which may ultimately prove destructive to independent living. Emphasis has been placed on individual autonomy at the expense of social solidarity, on the idea of the 'rational actor' rather than acknowledging how social and economic structures determine opportunities and on opportunity for 'efficiencies'. Doing so makes sense both to gain traction for the agenda overall and as a vehicle for levering power away from professionals and public bodies into the hands of those requiring support. But it draws on the same values of individualism and the notion that we alone are responsible for our lot in life that underpins declining public support for spending on social security and public services.

What I say here should not be misconstrued as an argument against the promotion of choice and control, direct payments, personal budgets and the like. Loss of self-governance must not be the cost of receiving support. But self-governance cannot be divorced from questions of how much support is available.

The case for society to invest public resources in disabled people needs to be at least as strong as the case made to give disabled people control over those resources that presently exist. For the reason's I have outlined I believe it may presently be weakened by placing so much emphasis on independence.

We can't alone turn society's values around, but we can learn how to harness that which is valuable and to avoid reinforcing that which is harmful. What I believe is required is a reframing that captures the notion of community, belonging, of interdependence, of relationships and reciprocity, of investment and return. We require a compelling narrative that persuasively conveys why an investment in disabled people's right to choice, control and participation is an investment not just in individual rights but in the common good.



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Independent Living and people with learning disabilities

The right to independent living is central to disabled people's human rights. However given the cuts to local authority budgets that right is under threat at present.

A report by the Independent Living Strategy Group, published by In Control in October 2015, found that despite the emphasis on wellbeing and choice and control in the Care Act 2014:

- Almost half (45%) of respondents to a survey said that their quality of life had reduced, and
- Almost a third (30%) said that they had experienced a reduction of choice and control over the past year.

The report found worrying evidence of caps being placed on local authority expenditure on care for disabled people. More concerning still is the fact that at least two Clinical

Commissioning Groups (CCGs) have formal policies which limit the amount they will spend on care at home to the cost of residential care for the disabled person.

A group of disabled people for whom the situation seems to have got much worse in the past year are those who previously benefited from support via the Independent Living Fund (ILF). The report from the Independent Living Strategy Group found that 14% of respondents who were previously ILF users had been told that they should expect less support in future, while the majority (56%) said they had not been told whether their support

would increase, decrease or stay the same. There have been terrible stories circulating of disabled people seeing massive reductions in their care package when their support transitions to local authorities – despite the assurances that this would not happen when the ILF closed.

The Care Act starts with a new principle of 'well-being' in section 1, which is supposed to inform all decisions taken about the care and support disabled people needs. The statutory guidance to the Care Act suggests that this principle is similar if not the same as the right to independent living under Article 19 of the UN Convention on the Rights of Persons with Disabilities – but Article 19 talks about a right to 'choice and control', whereas section 1 of the Care Act says nothing about choice for

disabled people, only control over the services they receive.

The Care Act requires local authorities to meet disabled people's needs if they hit the eligibility criteria. The broader duties on the NHS work in a similar way in relation to CCGs. However both local authorities and CCGs are expected to meet needs in the most cost effective way. This raises the big question – can it ever be lawful for a local authority or a CCG to meet a disabled person's needs in a way which cuts across their right to live independently in the community? The courts are likely to have to answer this question in the coming year.

It is vital that all disabled people and their families and friends know that they can access a solicitor to advise them on their right to independent living. Legal aid remains available to challenge local authority and CCG decisions, so long as the person meets the financial tests.

Steve Broach, Barrister,
Monckton Chambers
[@stevebroach](https://twitter.com/stevebroach)
www.monckton.com

ILLUSTRATION: TIM KEILTY, NEW PROSPECTS - @TIMJKEILTY

DRIVING UP QUALITY



Have you signed up to the Driving Up Quality code? The code commits providers to be open and transparent.

With requirements for Duty of Candour, Fit and Proper Persons, and the accountability of Company Boards, the Driving Up Quality Code enables providers to be open about the challenges they face in providing the best possible care, the culture within their organisation, and how well their Board members lead and run the organisation.

www.drivingupquality.org.uk



The independent supported living 'housework fetish'

Let's NOT pretend things are as good as they can be

Every week our team spends time with self-advocates, family members, paid supporters, organisational managers and leaders.

We hear people talk bravely and with heavy hearts about:

- the impact of reducing financial resources;
- families feeling excluded
- the struggle with and, the injustice of block tendering
- practice that limits any sense of individuality.

People tell us that Support for Living (people choosing where they live, who they live with, how they live and who supports them – see Reach) seems unrealistic in the present climate - that these aspirations are impossible.

Are we really on the verge of losing years of progress towards people living good ordinary lives? Are we going to accept the growing gap between stated values and practice?

We wanted to support people to discover a better way, to have the courage to risk new ways and to protect the rights of people to express their freedom to live good ordinary lives.

So, following a workshop with John O'Brien we published a paper 'Healing Integrity Gaps' highlighting people's stories, their struggles and desire to find a way of identifying and minimising the growing gap between values and practice. Importantly, we share some thoughts about how to achieve this.

Positive cultures, where such gaps are identified, grow stronger through thoughtful conversation among people with different positions and perspectives. It is through stopping and having these conversations that everyone will reflect and learn about a particular situation AND if necessary, find a better way of moving forward. Ten agencies joined our Create Positive Cultures Project to do just that!

As the starting point we suggested that the work would call on four capacities:

- First is the desire to support the freedom to live an ordinary life.
- Second is seeing and believing in people's capacity to live an ordinary life with the right support.
- Third is mindfulness and design thinking. The capacity to notice situations in which there is a disconnect between stated commitment to support people to live a good ordinary life and our actions.
- Fourth is a willingness to risk trying the design of a better way, reflecting and revising as you go along.

Time together triggered ideas for action! The project is ongoing and we'll be reporting on the work early next year. This process has allowed staff to reflect on what their organisations do more objectively.

What has become clear is that people value it when:

- we try and figure out the good intention at the core of people's actions
- people are supported to create and claim their own solutions
- we all keep asking: 'why' are we doing this?
- we seek answers to our 'Why' questions, in an open and non-confrontational way
- people practice the principles for Managing Emotional Well-Being which include:
 - ✗ Be compassionate and see the situation from another person's perspective
 - ✗ Listen and do everything you can to include ALL people
 - ✗ Make it your mission to work hard on relationship building even in the face of conflict and tension
 - ✗ Never sit on the fence when you know something is not right – Act!
 - ✗ Breathe!

Let's NOT pretend things are as good as they can be. Let's be honest, let's speak out, and let's figure out the best way forward together. Let's fight the right battles together.



Laura Broughton and Sally Warren, Paradigm. For more information about

Paradigm visit www.paradigm-uk.org or call us on 020 8870 8643.



Focus On : Special Interest Groups

The purpose of the H&SA Special Interest Groups (SIGs) is to share experiences and learning on a range of topics that affect the work of our members. Last year we focussed our groups on particular subject areas such as housing, care & support, housing brokerage and individual service funds.

We asked members what they wanted from future groups and most members said they want groups to be geographically closer and more flexible on subject areas, so this year we have set dates for SIGs all over the country and we want you to tell us what you want to cover in the groups. Is getting housing a problem, or making the money work? Do you want to develop Individual Service Funds, think about new ways to support people or talk about recruitment issues?

We have also started Driving Up Quality networks with our members to come together and discuss how you can shift the culture of your organisation, work transparently and drive up quality. We have also started an Operations Director network to bring members together who are in this role.

We now have Special Interest Groups in 5 regions meeting quarterly in :

- London
- Birmingham
- Manchester
- Bristol
- York

2016 Special Interest Groups dates:

LONDON			
Driving Up Quality	Feb 1 2016	May 23 2016	Sept 26 2016
General SIG	Feb 2 2016	May 24 2016	Sept 27 2016
Operations Directors	Feb 2 2016	May 24 2016	Sept 27 2016
BRISTOL			
Driving Up Quality	Feb 3 2016	Jun 8 2016	Sept 14 2016
General SIG	Feb 4 2016	Jun 9 2016	Sept 15 2016
BIRMINGHAM			
Driving Up Quality	Feb 29 2016	Jul 4 2016	Oct 3 2016
General SIG	Mar 1 2016	Jul 5 2016	Oct 4 2016
MANCHESTER			
Driving Up Quality	Mar 14 2016	Aug 1 2016	Nov 7 2016
General SIG	Mar 15 2016	Aug 2 2016	Nov 8 2016
YORK			
Driving Up Quality	Apr 25 2016	Aug 22 2016	Dec 5 2016
General SIG	Apr 26 2016	Aug 23 2016	Dec 6 2016

The cost to attend the Special Interest Groups are:

- Full H&SA Member Organisations free of charge
- Basic H&SA Member Organisations £25
- Non-Member Organisations £95

- Driving Up Quality network - free to all members

If you are interested in attending or would like more information about H&SA Special Interest Groups please contact mariana.ortiz@housingandsupport.org.uk

H&SA Annual Report 2014-2015

What we did in 2014-15

ADVICE: H&SA provided advice, consultancy and workshops to 3150 people, families and members.

MEMBERSHIP: We had 134 organisational members and 45 individual members.

DRIVING UP QUALITY: Over 300 providers and commissioners signed up to the Code and we now have 180 active participants.

KEEPING IT LOCAL: H&SA supplied a third year of services for a 3 year

Department of Health grant to deliver local training and support across the UK.

PEOPLE FIRST ENGLAND: H&SA supported the development of People First England to strengthen the voice of people with learning disabilities.

TRANSFORMING CARE: H&SA worked with DH, NHS England and the Winterbourne View JIP to support the development of the right kind of community services to keep people out of hospitals.

SPECIAL INTEREST GROUPS:

Specially tailored H&SA 'SIGS' were set up to give members the information they want, with the members determining the agenda.

EVENTS & TRAINING: H&SA had an Annual Conference and ran 97 days of training and events for our members and others. We also continued to promote and manage the use of the online training programme "Open Future Learning".

MONEY: In the year 2014-2015 H&SA received £318k income, and spent £325k.

WHERE THE MONEY WENT

£267k on paying staff and associates to do their work. We had 7 staff members during the year (inc People First England) and 5 Associates. No staff were paid more than £50,000

£39k for running events, marketing and updating our website

£19k for running the office and the charity

Our full accounts are available on the Charity Commission web site.

Rising to the Challenge

Independent Living and People with Learning Disabilities.

H&SA

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future directions
your decisions, your future...



We are a not-for-profit Community Interest Company working with individuals with complex needs, their families, commissioners, local communities, housing providers and social investment funders to design and develop personalised services.

We are able to provide a wide range of support and accommodation models such as supported living, specialist supported living and residential. These offer creative solutions to enable individuals to have increased choice and personalised support. Also creating opportunities for commissioners in response to the implementation of new service models and the national transformation plan for people with a learning disability.

For more information please contact John Exton via:

Future Directions CIC
Marie House, Oldham Broadway Business Park,
Broadgate, Chadderton, Oldham OL9 9XA
telephone: 0161 769 9000
email: info@futuredirectionscic.co.uk
www.futuredirectionscic.co.uk
FutureDirectionsCIC
@FDirectionsCIC



Housing you can build your life around

Everyone should feel happy and safe in their homes. Some people want to live alone, while others prefer to share, and some people need specialist adaptations. We work with people to find the home that is right for them.

By working with property developers, private landlords and families we can help more people find homes to meet their needs in a location of their choice. We help families find long term housing solutions for their loved ones by using a discretionary trust with Mencap Trust Company. GLH can help people to manage and maintain such properties.

Call 0845 604 0046
Email enquiries@glh.org.uk
Go to www.glh.org.uk



Twitter @GoldenLaneHouse

People and Places



People and Places (PAP) online communities are a secure platform for

vulnerable adults.

Somewhere to find friends and meet people with shared interests.

Users keep control over what and how much they share.

www.mypeopleandplaces.co.uk

Have you heard of the Challenging Behaviour Foundation?



We are the charity that supports people with severe learning disabilities and behaviour described as challenging.

Our vision is for anyone with severe learning disabilities who displays challenging behaviour to have the same life opportunities as everyone else.

We're making a difference to the lives of children and adults across the UK through:

Information: We have a range of information sheets and DVDs about understanding and supporting children and adults whose behaviour challenges, which can be downloaded or ordered free for family carers from our website.

Support: Our Family Support Workers can offer information over the phone or via email. We also have Family Carers' and Professionals' Email Networks, and a Family Linking Scheme.

Workshops: Our positive behavioural support workshops are run jointly by a professional and a family carer, to be delivered to any group working with children and adults with severe learning disabilities whose behaviour challenges.

Driving change: We work with a range of people to influence national policy. Current projects include the Early Intervention Project with the CDC, and the Winterbourne View Campaign with Mencap.

There are many opportunities for volunteers to get involved: Local Champions represent us at events; Family Link Volunteers give support to other family carers, and other volunteers fundraise or distribute leaflets.

To find out more, visit our website: www.challengingbehaviour.org.uk or get in touch by phone (01634 838739), or by email (info@theCBF.org.uk).

A new organisation for Quality Checkers



The Association of Quality Checkers

Later this year we will be launching one of the most exciting efforts to promote and encourage the work of Quality Checkers in health and social care services in England, Northern Ireland, Scotland and Wales.

The Association of Quality Checkers is a new not-for-profit membership association for disability organisations that provide quality checking services and a campaigning channel for our members and supporters.

The Association of Quality Checkers will:

- raise the profile of quality checking in health and social care services
- showcase best practice, themes and trends in health and social care
- campaign for employment, rights and citizenship for people with disabilities

Our website will be easily accessible and the place to find Quality Checkers in your area, read their profiles describing their skills, experience, and the services they offer, or simply get in touch.

For more information please email yvonne.furze@qualitycheckers.org.uk

ASPRICO
FOR FUNDERS AND PROVIDERS IN:
• LEARNING DISABILITY
• MENTAL HEALTH
• PHYSICAL DISABILITY
• OLDER PEOPLE

SUPPORTING PEOPLE AND PROVIDERS BY:
• Evidencing Value to Funders
• Demonstrating Compliance
• Supporting Inclusion
• Reducing Costs
• Managing Risk
• Managing Resources and Personal Budgets
• Promoting Person Centred Planning

www.asprico.com
Phone: 020 3893 7500



Exhibitors

Come and meet the exhibitors in the Cotton Room

Golden Lane Housing



Golden Lane Housing (GLH) provides individually tailored, high-quality and flexible housing services across England and Wales. We were established by Mencap as an independent charity to help tackle the immense challenges people with a learning disability face in finding a home. We have housed over 1,400 people in a location of their choice.

www.glh.org.uk

Time Designers Ltd



Time Designers Ltd is a small company co owned by Rachel Mason, a family carer with 2 sons with autism and learning disabilities. The products and resources that TD offer in the area of social care, education and health have been built from personal experience and first-hand knowledge so they will always be practical, meaningful and are designed to make a real difference.

www.247grid.com

Challenging Behaviour Foundation



We are the charity for people with severe learning disabilities whose behaviour challenges. We're making a difference to the lives of children and adults across the UK through: information about challenging behaviour, peer support for family carers and professionals, supporting families by phone or email, running, workshops to reduce challenging behaviour and speaking up for families nationally.

www.challengingbehaviour.org.uk

Future Directions CIC



Future Directions CIC is a high quality social care provider based in Chadderton in Oldham. Our intention is to drive the personalisation agenda so that each individual we support has their own contract/service agreement to meet their individual support needs.

www.futuredirectionscic.co.uk

Choice Support



Choice Support is a leading social care charity providing support to disabled and disadvantaged people with a wide range of needs throughout much of England. We've been around since 1984 and our aim is to support people to live better lives of their own choosing. We were one of the first providers to have helped disabled people and their families to take control and have 30 years experience of improving the lives of the people we support.

www.choicesupport.org.uk

Insane Logic



Insane Logic is the owner-run company behind MyChoicePad, a language development platform for mobile tablets using symbols and signs to reinforce language. Insane Logic not only creates the technology, but with its three resident Speech and Language Therapists, it devises projects and training programmes to help embed the tool across national social care organisations.

www.insanelogic.co.uk

Macintyre



We provide learning, support and care for more than 900 children and adults with learning disabilities, at more than 120 Macintyre services across the UK. Our diverse range of services includes registered care homes, supported living schemes, accredited training schemes and lifelong learning services, as well as residential special schools and a further education college.

www.macintyrecharity.org

Iplanit by Aspirico



iplanit is a leading cloud-based support planning service. This award winning solution has been implemented by over 70 social care services providers who support people in the disability sectors, older people, mental health and supported living settings across UK, Ireland and in partnership with National Disability Services in Australia.

www.aspirico.com

You Know



You Know is a free online, unbiased information and guidance site for health, social care and housing with support matters. We are an ethical business operating in the commercial sector and our funds will be raised by sponsorship and advertising.

Paradigm



Paradigm is a leading learning disability training and development agency. We have a passion for connecting people, ideas and action to ensure an ordinary life for all. We have a team of talented, committed and experienced

associates, including associates with learning disabilities who design training and consultancy in response to our customer's needs.

www.paradigm-uk.org

CHANGE



CHANGE is an international human rights organisation led by disabled people. We work to create opportunities for people with learning disabilities to become empowered citizens who can succeed, grow and participate equally in the community. We have a team of award winning designers and illustrators working alongside experts with learning disabilities who together create bespoke easy read resources and accessible materials in alternative media

www.changepeople.org

People First England



People First England is a new movement and an authentic voice for people with learning disabilities in England. We are working with other national and local groups of self advocates, families and allies, campaigning about the issues that matter most to all of us. We want to make sure that people with learning disabilities are heard loud and clear by politicians and policy makers.

www.peoplefirstengland.org.uk

H&SA



Housing and Support Alliance is a national charity and membership organisation working with people with learning disabilities, families, advocacy organisations, housing and support providers and commissioners. The Housing and Support Alliance works to create more choice and control for people with learning disabilities over where they live and how they are supported.

www.housingandsupport.org.uk

Conference agenda: Thursday 19 November 2015

9.00	Registration
10.00	Opening Session - Rising to the Challenge Gary Bourlet / People First England - @BourletGaryPFE Ian Birrell / Independent Journalist - @ianbirrell
10.15	The Challenge Session Alicia Wood, H&SA - @AliciaWood_HSA Siraaj Nadat, Changing Our Lives - @Siraaj_Nadat Dr Sara Ryan, University of Oxford - @sarasiobhan Laura Broughton, Paradigm Sally Warren, Paradigm - @SallyAWarren Neil Crowther, Independent Consultant - @neilmcrowther
10.55	Providers & Commissioners Rising to the Challenge Tom Noon, Cordis Bright - @Cordisbright
11.15	Tea & coffee break
11.40	Rights are more important now than ever Steve Broach, Monkton Chambers - @stevebroach
11.55	Can we afford for people with learning disabilities to live independently Professor Chris Hatton, Lancaster University - @chrishattoncedr
12.00	Question Time Chair: Ian Birrell - @ianbirrell Chris Hatton / Lancaster University - @chrishattoncedr Laura Broughton / Paradigm Steve Broach / Monkton Chambers - @stevebroach Sara Ryan / University of Oxford - @sarasiobhan Tom Noon / Cordis Bright - @Cordisbright

1.00	Lunch (1-2pm)
TIME	SESSION TITLE
2.00	Parallel Seminars
	WS1: Using the Care Act to make Independent Living a Reality
	WS2: Flexible & Outcome Based Commissioning
	WS3: Social Investment and Independent Living
	WS4: Housing Brokerage
	WS5: Good stuff that doesn't cost a lot
	WS6: Driving Up Quality
	WS7: Legal advice – book time with a solicitor
3.00	Parallel Seminars (repeated as above)
4.10	Conference wrap up Alicia Wood, CEO H&SA - @AliciaWood_HSA Gary Bourlet, People First England - @BourletGaryPFE
4.15	Conference film Tim Keilty, New Prospects - @timkeilty
4.30	End of conference

Parallel Seminars: (2.00 REPEATED AT 3.00)

WS1: Using the Care Act to make Independent Living a Reality

STEVE BROACH - @stevebroach
RHIANON GALE - @reeanon

The Care Act 2014 can be used to reinforce disabled people's rights to independent living. However at the same time the closure of the Independent Living Fund and reductions in funding for local authorities is severely threatening this right in practice. This seminar outlines the way the Care Act can be used alongside key human rights principles to ensure disabled people have choice and control over where they live.

WS2: Flexible & Outcome Based Commissioning

FRED GRAND - @DurhamCouncil
STEVE BARNARD - @DurhamCouncil

This seminar will present a theoretical overview alongside practice-based examples,

following an introductory overview to Outcome Based Commissioning. The session will address some of the challenges and culture changes this brings for commissioners. Included will be an operational view from a provider on how this works in practice.

WS3: Social Investment and Independent Living

STEVE HARRIS - @H_S_Alliance
MARK MCGOOGAN - @H_S_Alliance

This seminar will examine what social investing, and its very wide spectrum of risks and returns, actually means. The session will examine the implications for organisations that are thinking of pursuing social investment and the steps they might need to take.

WS4: Housing Brokerage

DIANE YOUNG - @dimensionsuk
BEN HARRISON - @unitedresponse

This seminar will focus on Housing Brokerage, a term which encompasses a range of

activities and has the aim of enabling people with disabilities (including people with more complex needs) and their families to understand the range of housing options available to them, and then secure the housing solution that meets their needs.

WS5: Good stuff that doesn't cost a lot

ANGELA CATLEY - @CommCats

The workshop will take the form of an accessible and engaging presentation with the aim of sharing stories about good stuff that doesn't cost much. Providers will share details of the imaginative things they are doing to support people to get the help they need to live the life they want to live.

WS6: Driving Up Quality

SARAH MAGUIRE - @SarahMaguire30
PETER KINSEY - @peterkinseycmg

Driving Up Quality is now just over 2 years old, with around 200 organisations and

local authorities signed up. This workshop is an opportunity to hear more about the different ways organisations have approached their self-assessments, and the improvements the process has made. It is an opportunity to listen, learn and share stories of what makes good support.

WS7: Legal advice – book time with a solicitor

ANTHONY COLLINS - @ACSLLP
TROWERS & HAMLINS LLP - @Trowers

Do you have some niggling legal questions you need answering? H&SA members, Anthony Collins and Trowers & Hamblins solicitors will be available throughout the day to provide free legal advice. They will be available to book a session with at the registration desk.

More information

For presentations from the sessions please visit the H&SA website after the conference.