

# **Building a National Network for Self-Directed Support**

**11<sup>th</sup> December 2017**

## **Main Issues**

- Assumption that all change is driven by austerity
- Attitudes
- Deficient culture
- People in organisations don't have (or take) the time for a personalised approach
- LA won't talk to us – don't answer emails etc.!
- LAs are taking basic control by devious means...
- Social workers are LA employees first, professionals second – don't argue for people, just do as instructed.
- Adversarial relationship
- Councils don't want to share control – “it's still out money”
- Local authorities / CCGs don't put their decisions in writing
- “Divide and conquer” – SW say one thing and do another
- Local health commissioners don't have policies to make personal budgets possible
- Providers don't 'get' personalisation – people still herded to time-wasting activities
- Systems too complicated to navigate – one size fits all
- Provision doesn't always match need
- People lack confidence to get help / help themselves
- Families scared to challenge
- Scared of the responsibility (money management) of being an employer and how to keep it going when family die
- People don't know how to challenge and fear repercussions if you do!
- Lack of everyone working together
- Isolation – people aren't in touch with anyone
- First pay rates and lack of career progression for PAs. Difficulty recruiting in some areas.
- Reliance on family and friends
- Re-assessed to exhaustion
- The closure of ILF is having a far-reaching consequence now – following reassessment of ASC
- Families and people don't know their rights and entitlements or about person-centredness – just accept what they're given
- Need to show what 'good' is! Lack of understanding and imagination – we need more stories, examples and inspiration. It needs to be independent.
- Knowledge at local level is not equal
- People already in poor services don't get a look in with personal budgets
- Creativity not encouraged or allowed

## **1. Systems and policies that make it hard, not make it happen**

### **What would help?**

- Budget cuts means we don't meet as a movement and confidence and networking reduced
- Stop the finance team making decisions above the assessors
- Coproduction – share our knowledge and help organisations to see how it works and do it well
- Myth-busting – info aimed at those who don't have a good understanding of SDS
- Identify where and why policies aren't working e.g. prepayment cards
- Wiser and more local commissioning
- Policies – having a bank of template policies that can be tweaked – and a personal link to how they work – mentors
- Common fact sheets, co-produced, that councils could take and use, maybe get ADASS support
- Connect with SCIE to see how they can help. E.g. rough guide to personalisation
- Find out council's policies for assessments

## **2. Professional and managerial culture (taking back control / deficit approach)**

### **What would help?**

- Local groups / people connecting together. Pulling common themes to challenge together.
- Ensuring there's always a buddy at meetings who knows your rights
- Citizen jury approach to creating a 'listening, learning and change culture'
- Leadership engagement and commitment – belief in change, driven from senior managers e.g. director attended partners course
- 'invisible' people, hidden in long term 'services' – difficult to access SDS and personalised support – support system and culture change
- Run more 'kindred spirits' courses
- Grow broad social movement to disrupt public services. Constructive challenge and co-design citizen jury example in Greater Manchester for homecare
- Recognise our world is now health and care and wider public services reform. Therefore develop a movement for empowering citizens, a new public service/citizen relationships embracing, for example, conversational approach, social prescribing, asset based pt activation, on the back of which personalisation will embed. Local alignment of voice with national group.
- Collaborative learning and development so people understand things from others' perspectives
- Circles of support to share good practice, connect people and advocate personalised support.
- A positive PR campaign on the potential of creative personal budgets and value for money
- Video or interview between very senior person and person/family
- Coproduction
- Set people going in as a critical friends
- Professionals working with self-advocacy groups

### **3. Knowledge (system, law, rules, possibilities etc.)**

- Ensure a transparent process in each locality
- Having good access to information
- Need to inform people and families – social media?
- Showcasing alternatives e.g. good organisations that take on employer responsibility for people
- Training – rights, the law and the system
- Working with solicitors on how to help people with their rights
- Using a network to tell people about their rights. Getting the message out.
- Learning and development for social workers on personalisation
- Need to use evidence better – learn from places doing things well. Look out, not in...
- Help tell people about the right to have a personal health budget in CHC
- Local organisations could share their knowledge, ideas, possibilities...
- Spread information about in stream – West Lancs Peer Support (independent support in each area)
- ‘Pass it on planning’ revived to help people with solutions
- Accessible information

#### **4. Confidence, skills and support of people and families**

- Representation (not advocacy)
- Investment in leadership programmes – collaborative e.g. partners in policymaking
- Training – skills you need to navigate the system and make sure you know your rights
- Self-advocates and carers working together
- Pass it on planning – people who have experienced support planning, get training, agree to plan with other families
- Self-advocacy, peer advocacy, mutual support
- Putting money into self-advocacy groups
- More training from self-advocacy groups – co-production –done with not for!

## What I can do...

- Jenny Cater - I can offer my experience of self-directed support without a personal budget. Also creating a self-advocacy group.
- Vicky Buckingham
  - Which?
  - Expert by experience.
  - Confident in using social media and ipad/iphone.
  - Listening to people who use services.
  - Peer travelling support buddy.
  - Self-directed support experience.
- Michelle Evan
  - I can share my lived experience and knowledge about “what good support looks like”.
  - I offer my experience of DPs for younger/older people. 1-1 support with DPs and the system.
  - I can share my story of ‘getting a life’ and leaving home.
  - I offer NCAG!
- Seb – Peer support. Skills and knowledge around personal budgets gained through lived experience. Offering from someone else. I know William Case – YSM.
- Kate Sibthorp
  - personal experience of DPs, managing PAs etc. happy to talk to people.
  - One-to-one support with assessments, planning etc.
  - Running events – appreciative inquiry trained.
  - Work with TLAP and NCAG – something through them perhaps.
- Kelly
  - Advice, ‘lived’ experience, share contracts, places to recruit, what has gone well – not well.
  - What could budget cover in future.
- Darren Hayward
  - manage the network Facebook page
  - what will people do if the personal budgets are cut and maybe I would like to start a group myself at some point on social media (much cheaper than starting an office based one where you have to spend money on an office space and/or a room)
- Lawraine - Create a facebook page
- Carey
  - Can support some gatherings, use social media etc.
  - Local links and connections and coffee
- Gaynor
  - Admin support with webinars. Facebook page.
  - Admin support with surveys/research on policies not working. Similar to prepayment cards evidence.

- Wendy
  - Helpline support
  - Admin/research finding information
- Will Case – I know someone who can offer...
  - Easy-read information (Change)
  - Peer support (Sebastian Lynn)
  - Brokerage recommendations (ILBP Bury and Instream)
  - Health and education plans (Council For Disabled Children)
- Janette Cunliffe – Wigan Council
  - Good working relationship with CCG to promote personal health budgets, happy to share
  - Development of best practice. Leads within social work teams to promote and evidence a person-centred approach.
- Nick Dixon
  - Leadership around growing a collective voice in Greater Manchester to positively disrupt the public services
  - Engaging GMCAs transformation programme around 'Care at Home' with innovative design solutions generated by a wide range of voices outside of the system (citizen jury / collaborate Out Loud / ADASS / Manchester University)
- Angela Boyle
  - North West connections (local and regional) in health and social care, and particularly providers of care of support.
  - National connections in health and social care – can support the drive agenda towards movement for change.
  - Influence across C4CC partnerships and ability to connect orgs, people, common work/agendas.
  - Housing connections in north west to engage in wider agenda.
  - Qualified executive coach and mentor – can support leaders to do / see things differently – possibly providers?
- DR UK can offer access to our fact sheets, guides and other resources
- John Lawraine - A meeting room in the north east for a network get together
- Will Case
  - Help with personal assistant recruitment
  - Disability equality training
- Zoe Porter – I can offer connection to Greater Manchester and to national NHS England programme and sometimes resources!
- The 'Partners' email network as a resource for info and support
- Katy Moulton – legal advice re: community care / court of protection issues
- Andy Gilbert KDC
  - Support building of local (Liverpool city region) networks – extending invites/connections
  - Help with rebuilding ties and connections old/new

- Rediscover and share history and past best practice
- Supporting research with local people to establish what is working/not working
- Supportive of community up/grassroots/spider webs
- Support and encourage social media activity
- F Smith - Support development and delivery of key messages. Bring case studies to the table.
- John, In Control – clear simple info on rights
- MIXIT - advertise the group on youtube through MIXIT TV
- Virginia Webster
  - Group / individual support / signposting etc. using:
    - WhatsApp group
    - Facebook group
    - Twitter – linking information etc.
    - Texting support and phone calls
  - Any activity using social media / internet
  - I can give this time early mornings and late in evenings
- Cascade info to south East network of disabled people's organisation
  - share good practice
  - share case studies
  - send positive comms around SDS
  - share experiences of PHB
  - showcase solutions
  - PA noticeboard
  - Continuing independence agency

## What others could do...

- Jo Fitzgerald who leads PHB peer and lived experience work is thinking about how people with PHBS who have skills and interest in being active can get involved (NHS England)
- Community Cats @ Comm Cats
- I can get other individuals and organisations signed up by promoting the network idea to DR UK members
- Connection to community led support – personalisation and systems change
- Liz Wilson, Dimensions – I've got a course to help new employers – disabled people or families – get the skills and confidence they need to recruit and manage a staff team. Happy to share materials or train trainers (funded by Skills For Care)
- Liz Wilson, NVFF – Still have the network and we are in touch – can let people know about this and give opportunities to get involved
- Liz Wilson, Dimensions – holds some family info sessions about tights and negotiating the system. Could open up to all.
- Liz Wilson, Dimensions – can offer meeting space in some parts of the country.
- Liz Wilson, Dimensions – Could make some contribution (probably not cash) to source kind of Kindred Spirits to promote systemic and cultural change.
- Possible training link? Supporting knowledge sharing and connection
- Janette Cunliffe, Wigan Council – Ideas for a person-centred approach to assessment and support planning
- Kelly – who do I know/what
  - In Control – Julie
  - Persons from Sharing Knowledge – persons speaking too
  - Inclusion North? Parent Advisors
  - People Hub and persons who have offered advice on PHB over facebook/email
  - CCG complaints email!
- Dimensions, Liz Wilson – produce series of “facts for families” – can share those that aren't specific to families in Dimensions only
- Ask partners graduates specific questions raised today to get a wider view.
- Alzheimer's society range of resources
- Skills 4 care leadership and workforce devt
- Irwin Mitchell is a national law firm so advice from solicitors in other offices, training on legislation etc, fact sheets and template letters
  - Irwinmitchell.com – ‘protecting your rights’
- F Smith
  - bring other key players into group including colleagues
  - learning from other areas where it may be working and conduct to others i.e. CSA
- Les Scaife, West Lancs Peer support – independent advice

- Ian Merrill Spice - I will go away and work with colleagues to think through how time credits could be used to promote self-directed support. We could then approach specific LAs to explore opportunities to develop the idea.