User-driven commissioning and disability as an asset

– or how to reduce health inequalities together?

Bernd Sass / Disability Rights UK, 12th May 2016

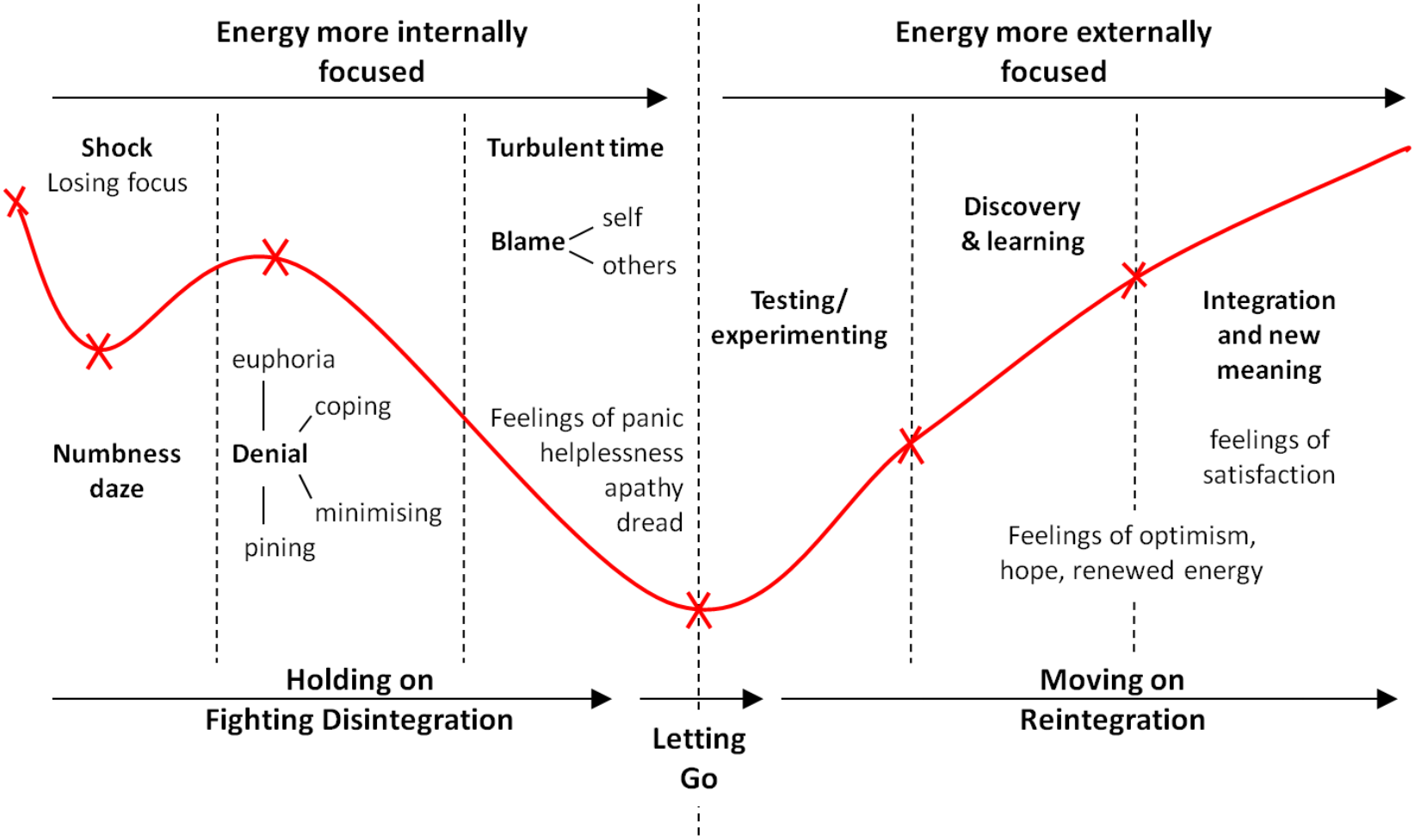
CHANGE

Shaping Our Lives National User Network of Service Users and Disabled People

Disability Rights UK

Win Win Alliance

The ‘Change Curve’



Kübler-Ross

Picking up from change curve

- Drive to Achieve vs. Fear of Failure: Why do **disabled people / disability** and **agency** largely not feature at EXPO or major programmes, eg FYVW, BCF, Devolution, NHS Citizen?
- Peer support popular in some places but largely used as a cheap means to promote and ‘showcase’ self-management (to help discharge people) (one-way) = **change targets** (eg TCs)
- Little understanding of peer support as an active, rights-based approach to co-production to improve whole systems (two-ways) = **change agents/sponsors**

How the system addresses patients & disabled people (at best)

Why not simply translate those global findings into further narratives or even metrics for contracting?

- Staying well (prevention, health promotion, self-care)
- Getting better, feeling better (outcomes of care)
- Right care from the right people (clinical quality, safety)
- Treated as a human being (humanity of care)
- Information, communication and having a say (involvement)
- Being supported (incl. support for carers and relatives)
- Safe, clean, comfortable place to be (environment of care)
- Right treatment at the right *time* (timely access)

- Right treatment in the right *place* (physical access)
- Not being passed from pillar to post (continuity of care)
- Continuous care (after-care)
- Support for independence (self-care)

Because we need to delve a lot deeper and enable real communicative space and impact continuously

Co-producing outcomes (1)

•Ask people ‘What makes you feel better?’ and ‘what role can I (as professional or peer) play in this?’ ‘And how can we make sure that this happens?’ But this is not enough!

•Commissioning needs to incentivise agency by people outside of the service so resources can be tied in with community support

•Peer support, self-assessment and self-referral need to be integrated into contracts

•Co-production does NOT require new resources but new ways of working, contracting, releasing time and questions

Some more (older) arguments

- 70% of NHS spend on disabled people and so freeing up resources leads to more time for support planning – communicative space fosters engagement and reduces ‘failure demand’

- People tap into their own networks (and those of their peers) and integrate and bring support together while opting for less intensive care and treatment

- Collective spaces plug the gap between ‘individual choice’ and ‘wider determinants’ (of those with stark inequalities)

Co-producing outcomes (2)

- ESRC funded Disability Rights UK for research with University of Bristol: ‘Tackling Disabling Practices: co-production and change’
- User-driven commissioning - tried and tested approach to gather and translate people’s lived experience into outcome measures for contracting
- LE teams to prompt ‘letting go’ / discovery / learning, eg role swapping: ‘time credits’; WRAP - applied to frontline teams
- Models for communication deficiencies (in system) leading to misdiagnoses and low cancer detection rates for (learning) disabled people


Access
Not being understood
Service not meeting needs
Dropping out
Escalation of problem
Lack of independence, and inability to move on
Stuck in services
We know why we are here…
Why are you here?

Co-procuring 5-year CAMHS contract

- 20% stake upfront to Lived Experience team of CYP with MH problems (and carers) – 14 sessions in 8 months
- Inwards stage: shared life stories to map out risk and protective factors in feeling good
- Explored current services / support – (peer) advocates
- Vision for landscape of ideal services and (peer) support
- Confident / independent / competent to step up / down
- Outwards impact: trained up to co-produce ITT questions, metrics, co-assess bids, co-conduct interviews (20%)

  a) refreshed service specifications and metrics (eg £5)

  b) from PQQ right through to contract award, mobilisation, outcomes-based payment and annual contract variations

Peer modelling in the NHS – Disability as an asset towards WDES

Disability Rights UK – exploratory research

1. Online survey, Sep 14 - Jan 15: 942 responses (disabled NHS staff: 75% + AHPs, failed returns; mix of impairments / geo; dual identity, eg LGB&T: 14%):

http://www.nhsemployers.org/case-studies-and-resources/2015/05/different-voices-different-choices

Non-disabled response/call: increase diversity in key functions (management, HR/OD, OH, investigators)

What the NHS does well

53 per cent

The NHS supports a substantial number of disabled employees, as 53 per cent said their experience at work was a good one.

84 per cent said they were open at work about their disability.

Many managers deploy good practice around disabled colleagues.

When disabled staff groups are established, they are well regarded by senior management.

DIFFERENT VOICES, DIFFERENT CHOICES:

Listening to the views of disabled staff in the NHS

Key themes from a recent Disability Rights UK survey, which brought replies from over 900 NHS staff.

What the NHS could do better

16 per cent of respondents said they had either 'protected characteristics', such as mental ill-health, asthma, memory or autism.

4 per cent of all respondents had learning disabilities and 18 per cent reported mental ill-health.

41 per cent felt their disability meant career progression was hampered.

A key issue identified was the monitoring of disability-related sick leave.

While many said they had supportive managers, HR teams and occupational health arrangements, it is reliant on the individual rather than systems.

16 per cent chose not to declare their disability, possibly to avoid future career impact. That is low compared to other industries, but NHS employers may want to improve further and reduce this key factor to become leaders in this field.

16 per cent

Disability Rights UK – qualitative findings (reflected)

2. Interviews – in-depth, non-standardised, n=13:

- Impairments: newly diagnosed - cerebral palsy

  Posts: Clerk – Senior Director – NHS 111 clinician
- Majority had disability-related leave not listed separately – triggering sanctions or reduced A/L
- Patchy implementation of Disabled Staff groups
- Failure to understand and use Access to Work
- Poor practice around delivery of E & D training
- Fear around disclosure - compounded
- Managers' mixed abilities to support disabled staff
- Benefits of lived experience at planning and delivery

Disability as an asset (DAA)

- Reframing the discourse/social action campaign: not just supporting disabled staff to ‘catch up’ but recognising DAA

  Co-production between staff and patients to help break down boundaries in strategic planning and frontline delivery

- to understand and improve accessibility, disability-related absence, Access to Work, balanced ‘disclosure’
- but also: create communicative space (trust, rapport) conducive to peer support and patient-/staff-driven initiatives
- experience/outcome measures for staff-patient interface
- NHS patients: most diverse group for inclusion agenda..

DAA as social action campaign towards WDES and beyond

- DAA facilitated with four local delivery teams identified by two-pronged approach to NHS employers and disabled staff groups (real drivers) – also tying in with Vanguards
- Upfront commitment to selected outcome / clusters
- Co-producing models for internal change (eg reasonable adjustments) and outwards-focused improvements (eg patient contact, employability)
- Models to also feed into further WDES metrics by 4/2016
- NHS as exemplar employer, disabled staff role modelling to people out of work / not in the NHS, intersectionality

NEXT STEPS

We are keen to speak with disabled colleagues about their views and experiences on these same issues:

1. Disability Rights UK online forum on ‘DAA’

2. And beyond through NHS E channels and Equality & Diversity Council subgroup on Leadership & Workforce overseeing the development of the Workfoce Disability Equality Standard

Questions for discussion

- What is your response to the research and developments?
- What are your thoughts about a Workforce Disability Equality Standard (WDES) and proposed metrics?
- How do we ensure ‘social action’ follows identification of issues, eg greater proportion of BME staff involved in disciplinary procedures but no system action taken at scale?
- How can Disability as an Asset be developed in NHS trusts?
- What actions can each of us take to ensure that disabled NHS staff will be directly involved and drive their own projects?

- What can you do to spread information and support disabled staff groups on this agenda?