

The Receiving End – Everything you wanted to know about Integrated Care but were too afraid to ask !

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- Congenital CMV infection (more recently ?genetic condition)
- Severe learning disabilities
- Cerebral visual impairment
- Epilepsy
- Physical disabilities – wheelchair user
- Autistic features
- Severe sleep disorder
- Recurrent chest & ear infections



Outline

- Some background about Integration
- My perspective on the problems
- Examples
- Solutions
- Coproduction, coproduction, coproduction

Integration

- 'The fragmentation of health services for children has been recognised as unsatisfactory for at least 15 years'.

'Building a combined child health service'

Margaret R S Barker, R J Purvis

Archives of Disease in Childhood **1992**;67:1298-1301

- We have known about this for more than 40 years
- I have seen no change on the course of Matt's life. If anything, things are worse

Integration

- Easy to blame austerity measures
- Not the underlying cause but has undoubtedly has made things worse
- Impact of austerity on families with disabled children in Europe. Horridge K, Dew R, Chatelin A, *et al. Arch Disease Child* 2018;**103**:A1.

Integration

- ‘There are frequent complaints of 'buckpassing' and inaccessibility of the service from general practice, social services and education, and parents are completely bewildered by the divisions and splits which prevent their children receiving an effective service’.
- Describes our life for the last 18 years
- If this is what it had been like for me as a Consultant in Paediatric Neurodisability – what hope do other people have?

Why?

Systems are organisation, not person, focussed

- Service-driven responses – fitting people into services
- Little choice and control if a service exists at all
- Not always clear which service should be responsible
- Services operate in parallel rather than co-operating
- Each service is responsible for their own budget – there is no incentive to spend, even if it means savings for another service or a better outcome
- Over-burdened professionals losing sight of the person
- Poor use of resources
- Endless time spend on gate keeping measures – meetings, reports ...



A couple of examples from our
own experience

1. Extreme 'sandwich' caring

- Children age 6, 5 and 1
- Grandfather no.1 diagnosed with metastatic cancer – hospice within 3 months
- Whilst arranging his discharge to our home, grandfather no. 2 had stroke – hospitalised out of the region
- Asked for help
- Not just lack of service, but lack of humanity

2. Planning for adult life

- Started looking when Matt was approaching 16 (year 11)
- School day place only post 18
- Adult residential component unavailable (full) and concerns about quality of residential provision
- Nearest alternatives for VI / complex disabilities Edinburgh or Harrogate (~2 hours away)
- Education said they would only fund a place if it was of demonstrable educational benefit
- Social care were clear that Matt should stay in education
- No involvement from health even though we had Continuing Care funding (delegated to social care)

Our solution

- The suggestion we offered was a personalised package at home (late 2016/early 2017)
- Also asked if this could start prior to 18 because of concerns about respite provision (bruising and declining quality) and actual benefits of Matt attending school
- Asked for help to put this together – not forthcoming
- Was asked to write a Business Plan – still refused
- Was told that it would need a ‘best interests decision’

Achieving a 'PHB'

- Discovered PHBs by accident and the legal right
- Challenged the refusal
- Was told that his care package would have to go out to agency tender – declined (previous experience of agency care had been poor)
- Submitted a formal complaint through commissioning
- Wrote to NHS England about 3am around New Year
- Eventual obtained agreement for a PHB more than a year after asking but still do not have control of the budget (e.g. training)

The difference a PHB has made

- to Matthew

- Matthew is happy and doing things he loves, that matter to him
- He is outside every day for hours
- He does not have to be woken up in time for school if he has had a bad night
- No vomiting on school transport
- He avoids distressing things (lunch hall / assembly)
- He gained 4kg in 4 months after leaving respite at school (more than he gained in the previous 16 months)



The difference a PHB has made

- to the family

- We can actually leave the house!
- Sleep
- Normal family things like leaving the house after 8pm in the evening
- No longer a logistical nightmare doing simple things like going to a parents evening or visiting my daughter at University
- I have a life again – work and home
- NHSE Strategic coproduction group
- Still a work in progress

Despite everything

- Obtaining a PHB was difficult, but it has been the process that has been wrong and not the PHB itself
- Having control has been hugely positive for all of us
- The number of people that care for Matt has reduced to 6 (compared to 30+ classroom team / transport / respite). Different relationship.
- Cheaper than a residential facility / college with transport and agency care (more than £40k a year)



Other examples – NHSE website

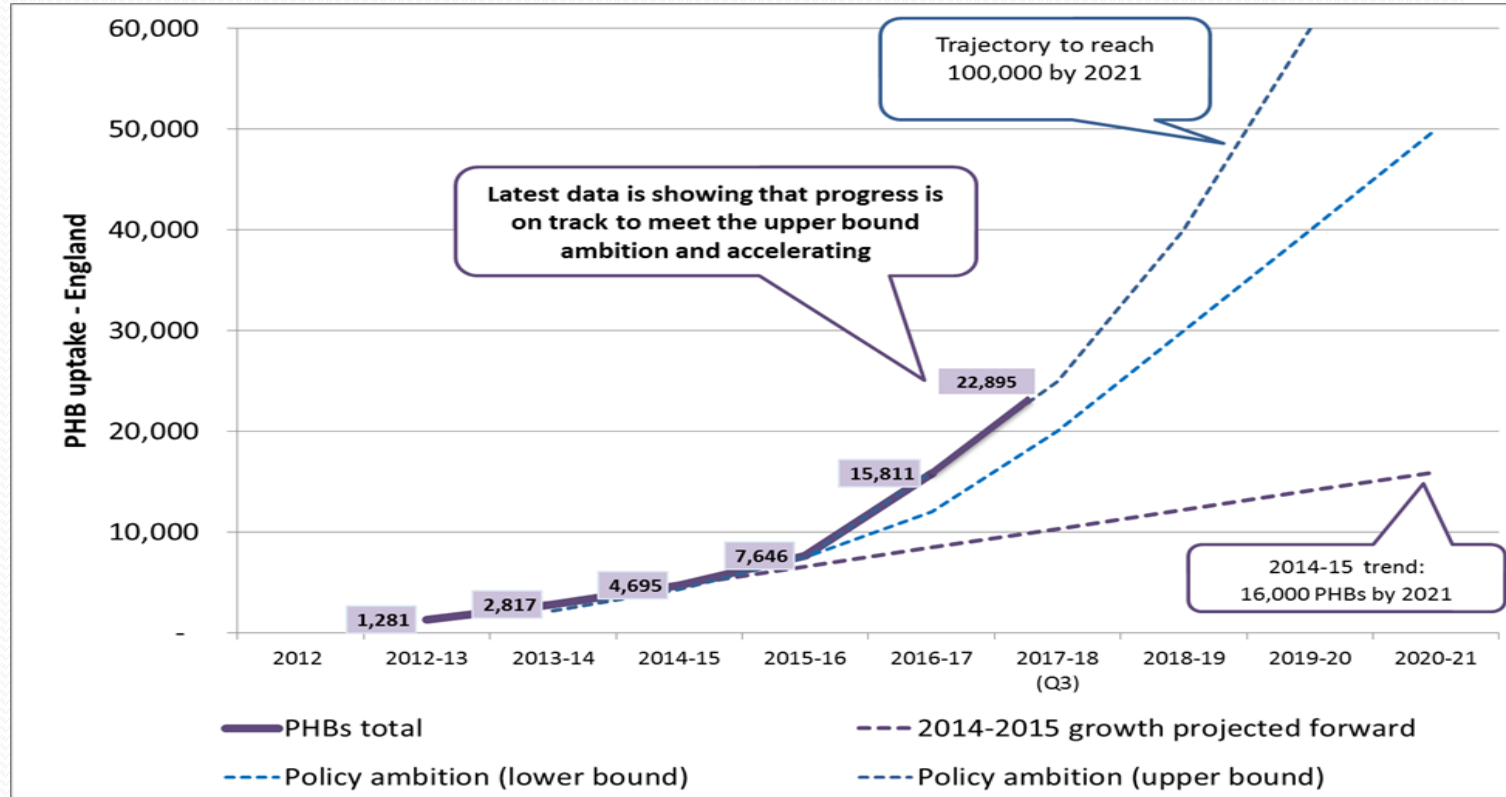
- Dylan's 5k wheelchair vs 3k wheelchair
 - powered footplate lowering to the floor on its own and a reachable charging point
 - Allows independence of carers, £13k system saving

<https://www.england.nhs.uk/blog/there-are-wheels-within-wheels/>

- Jackie's £3k assistance dog

[https://www.england.nhs.uk/personal-health-budgets-phbs-in-action/patient-stories/jackie-and-kingstons-story/](https://www.england.nhs.uk/personal-health-budgets/phbs-in-action/patient-stories/jackie-and-kingstons-story/)

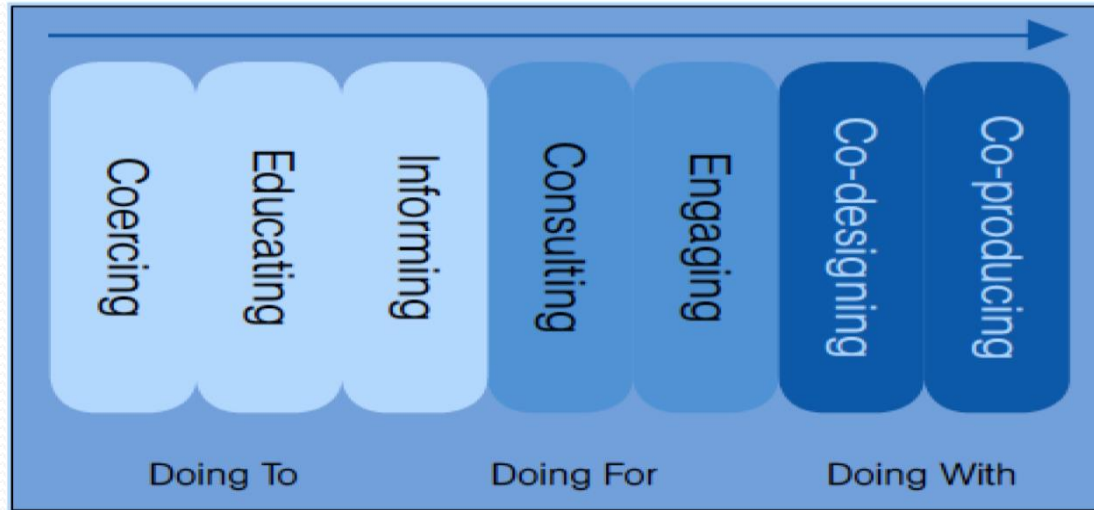
PHBs progress towards 2021 ambition



My perspective

- Frustration of watching 18 years of different 'top down' initiatives with no visible improvement
- Ineffectual government directives telling services to 'integrate'
- Success has come with from bottom up approaches (PHBs and other initiatives originated from people on the ground)
- Truly involving people on the receiving end in designing and delivering solutions

Coproduction



The New Economic Foundation's (NEF) alternative 'Ladder of Participation' (Slay and Stephens 2013).

Adaptation of Arnstein's ladder

Co Production

- Change in mindset for professionals
- We are used to people coming to us with a problem and we are the expert with the solution
- Uncomfortable / radical that the person might provide better solutions themselves
- Example from Africa ...

Strategic Coproduction Group

- A small group of people with diverse ‘lived experience’ who have undertaken training and selection to work with NHSE England on a national level.
- Meaningful involvement in
 - shaping NHS Personalised Care policy,
 - developing and delivering training to professionals,
 - championing Personalised Care
 - providing feedback to NHSE about how things are working ‘on the ground’.

Going forward

- ‘What Matters to You?’
- Do not plan design or deliver anything without meaningful input from those of us on the sharp end
- We often have really good ideas and see things in a way that even the most educated well meaning professional could not
- Thank you for listening