Institute of Education

UCL

Crossing the divide: extending life chances for young adults with chronic health conditions through distributed learning and innovation

Alison Fuller, Susan Halford, Kate Lyle and Rebecca Taylor

LLAKES conference 15-16 November 2018

University of Southampton

LLAKES CENTRE FOR LEARNING AND LIFE CHANCES IN KNOWLEDGE ECONOMIES AND SOCIETIES

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Introduction – youth transitions

- Increasing concern about the challenges facing young people transitioning to adulthood - focus on the labour market, the establishment of a career and financial independence
- Insecurity facing all young people making transition shaped by social background - economic, social and cultural assets differentiated through class, gender and race, at least.
- Our research focuses on young people with long-term health conditions
- Previous research emphasises that ‘transition’ is non-binary and non-linear but for these young people, it occurs overnight.
- Example: 90% of diabetes patients attending children’s outpatients. Within two years of transfer dropped to 50-60%
- Consequences for education and labour market outcomes
- What might be done about this?

What might be done about this?

- UK intervention established by a paediatric consultant in response to the outcomes that she observed in practice
- Not mandated but ‘employee driven innovation’ that has subsequently gained considerable traction across UK healthcare.
- Our argument: intervention has been driven forward through fostering boundary permeability and processes of ‘distributed learning’:
  - health care professionals
  - young people
  - parents/carers
  - schools

Case study: ‘Moving up’

- An intervention for young people with chronic conditions that supports their transition from paediatric care to adult services in the NHS
- Developed by a clinician and nurses working with young people
- Generic programme – not specific to condition – based on a series of questionnaires
- Patients and MDT work through questionnaires together – facilitates co-production and embeds transition in day to day practice
- Received no funding, yet has been implemented widely within the Trust and beyond
- Pseudonyms for the case, location and individual participants have been used throughout this paper.

Data Collection

- Qualitative interviews;
  - 7 interviews with Moving up steering group members,
  - 2 interviews with senior clinicians with experience of using the programme

Participant observation:

- 26.5 hours of observations:
  - day to day work of delivering the innovation;
  - Insight into how the programme was constructed and presented

Empirical findings

Empirical evidence from our case study shows:

- The problematisation of service provision and innovative solution emerged through the practice of HCPs and their unique position in relation to patients and the organizational system
- The value of the innovation comes through facilitating distributed learning among different stakeholder groups across permeable disciplinary, organisational, generational and sectoral boundaries

How do we know there's a problem?

- Problematisation of service provision for young people came from the reflective practice of a senior consultant - Seema
- Learning is inspired when practice stops becoming habitual – disruption in flow (Knorr Cetina, 2001)
- Practice disrupted by inequalities produced through service provision
- Highlighting case:
  - A patient she had been working with for several year going to University in Scotland
  - Seema worried that the patient did not the right skills and knowledge to manage his condition independently

Specialist analysis

- “I was thinking…’hmm, I’m not sure how much you know about your condition, because you really don’t know that much, and if you go up there, it’s a long distance – and because I’ve got this feeling with adults, you know, you just become lost in this big crowd of people, and unless you know who to contact, what they need to follow up’ … So I was just concerned that he wasn’t going to get the correct standard of care.”

Seema, senior consultant

Practising differently

- Kept the patient under her care, despite his age, to allow time to prepare him to move towards the independent care:
- "*I thought, he needs to know about his condition, its long term outcomes, who to contact for help and what needs to be monitored, and make sure that that was all being done. So I said, "Well, let's get you ready for that." So I thought, "Well okay, let's hold onto you." So I held onto him for another two years while he was up at uni, 18 months to two years, before I transferred him, and made sure that all these plans were put in place."*

(Seema)

Agency in action

- Inspired reflection on service provision for young people with chronic conditions more generally

- *“I thought, well okay, he’s not going to be the only one that’s going to have this issue. It’s going to be happening to other people as well… I thought well, I want to make a difference, and there was an opportunity to do something on transition. So look, why don’t I look at the transition aspect here … I’ll do transition, get something in place for everybody and we’ll go from there.”*

(Seema)

Value of expertise

- Value of position of the HCP in conceptualising the problem:
  - **only** the HCP who could see this problem
  - Patient does not have experience of adult services to foresee problems
  - Not visible from top down - transition is a problem that falls **between** – difficult to see in siloed system
- Conceptualisation of problem requires insight HCPs - so too does constructing innovation

Constructing innovation

- Knorr Cetina (2001) - differentiations in practice stimulate learning by inspiring a ‘chain of wanting’ - expert seeks greater and deeper knowledge about the subject.

- Disruption inspired focus on academic and policy literature, and the practices of colleagues for a solution:
  - “First I went to the literature to see what the recommendations were, and I thought, there’s loads in the literature, so what I’ll do is I’ll see if there’s any tools. But there were no real tools that you could use. So I thought, well, I’ll go to my colleagues, you know, cystic fibrosis, cardiac and all those people, and see what they’re doing. And again, they’re all doing transition but not hitting all the elements that are recommended in the programmes, in the policy documents and in the recommendations sent down by Department of Health”

    (Seema)

Enrolling stakeholders

- Knowing that implementing the innovation would be challenging Seema found ways of 'selling' to colleagues:
- *"So I said to the cardiac team, "Look, you've got Safe and Sustainable [a national target] and you've got to get transition… why don't we join our work together, save resources and work together and develop something?" And they said, "Yep, great." And then I went to the cystic fibrosis team and I said, "You guys have got to get a transition programme in place. What have you got? Nothing? Well, why don't we work together and do this."*

(Seema)

Navigating resistance

- *“Some of [the doctors] said, “Over my dead body, because it’ll be really difficult [to use].” … And then there was another one that said, “I’m already doing it. I’m already doing transition” ... I’m thinking, how can I get the doctors to start doing this? So I [put] big posters in clinic, you know, huge posters… thinking, well, hopefully some of the patients will have the nous to ask. So that’s what they’re doing - one of the guys said, “I didn’t want to do it but a couple of patients have asked so I’ve started them on it.”” (*Seema)

Distributed learning across permeable boundaries

- Essence of Moving Up: inspiring learning among the varied groups involved in the care of young people across boundaries:
  - HCPs
  - Young people themselves
  - Parents/carers
  - School

HCP learning

- Programme inspires HCPs to learn about new ways of delivering care, or deliver care in ways that they have previously overlooked:

- *“I’ve been surprised because I thought, “Oh that question’s a bit personal, they won’t want me asking that,” but actually they really quite like that bit about relationships and things like that- to have a chance to actually discuss it”* **James, Consultant Psychiatrist**

Young people learning

- Young people encouraged to learn more about their condition:

- *“There was a cystic fibrosis child, 16, who was going through the questionnaire and [saw questions about fertility and said] “hahaha, this has got nothing to do with me.” But he can’t have children naturally. He’s going to need assisted fertility. But he didn’t know. And it had been discussed with him in the past… Or maybe it had been mentioned but it hadn’t gone in. So because it was on the questionnaire it was like a punch to his stomach, suddenly he took more of an interest in the programme, and the next time he came, he knew everything about everything.” (*Seema)

Parent/carer learning

- Parents learn how to assist their children:
- *“Parents can be reluctant as well, I think, if you start talking about, ‘you have got a child with a chronic illness’ and they want to protect them, and they have done all of their caring for that child and … their perception is that you are trying to take away that from them. So by introducing it early [through the programme] and making it clear you have got seven years to do this [transition] and this is just about educating your child not pushing you out I think that is really helpful.” (***Julia, a respiratory nurse)***
- .

School learning

- An important part of the programme is to ensure that the expectation for patients at school are the same as those for their peers, and that they should have the same opportunities and life-chances:

- *“We’ve had patients on haemodialysis, and the comment from the school is, “Oh, they’ve not been going to school for months. Oh, it’s alright, they’ve got a kidney condition.” You think, no, they should still be going on the days that they’ve not got dialysis. They should still be achieving. … I said [to the parents of one patient] “We don’t want the school to have low expectations, so we’ll talk to the school.” ... So it’s just to make sure they reach for those stars, because I think that’s really important.”* **Seema, Consultant Nephrologist**

Conclusions

- Disrupting institutionalised binary and linear services that reinforce inequality
- Youth transitions as non-linear and reflexive
- Mobilising insight from day to day practice to conceptualise transition as a process rather than an event
- Enrolling diverse stakeholders across disciplinary, organisational, sectoral and generational boundaries
- Deployment of concepts and tools which facilitate boundary permeability and processes of ‘distributed learning’

Project publications

- **Publications from the wider project, for further interest:**

- Halford S, Fuller A, Lyle K, Taylor R (2018) Organizing Health Inequalities? Employee-Driven Innovation and the Transformation of Care. *Sociological Research Online* 1-18 https://journals.sagepub.com/doi/abs/10.1177/1360780418790272

- Fuller A, Halford S, Lyle K, Taylor R, Teglborg AC (2018) Innovating for a cause: the work and learning required to create a new approach to healthcare for homeless people. *Journal of Education and Work* 31(3) pp. 219-233 https://www.tandfonline.com/doi/abs/10.1080/13639080.2018.1447654