Developing Theory for Person Centred Approaches: Terms of Engagement

Helen Lloyd and Debra Westlake
The presentation

- Integrated Personal Commissioning (IPC) evaluation - one Person Centred Coordinated Care (P3C) intervention in the Southwest of UK
  - Operational model and methods
- Emerging (candidate) theories -
  - mechanisms to overcome contextual barriers
  - a tentative model of pre-context for P3C
  - social network (co-production) as a mechanism for change
- Links to middle range theory
- Conclusions
IPC as an example of person-centred approaches

**Individual level experience of IPC**

- **A community and peer focus to build your knowledge, confidence, and connections**
- **A different conversation with the people involved in your care focussed on what's important to you**
- **A shift in control over the resources available to you, your carers and family**
- **A proactive approach to improving your experience of care and preventing crises**
- **A wider range of care and support options tailored to your needs and preferences**
Research methods

Two demonstrator sites in SW England

- Quantitative – measures of patient experience (P3CEQ), wellbeing (WEMWBS), activation (PAM)
- Qualitative – participant observations, semi structured interviews, focus groups (20 participants, 12 practitioners) over a year. Age range 52 – 86 years
- Role of coproduction group in data collection, analysis and theory development workshops (upcoming)
- Thematic inductive primary analysis using data management software (QSR Nvivo 11) and framework method (Ritchie and Lewis, 2003)
- Realist evaluation approach for theorizing (Pawson and Tilly, 1997).
## Participant responses when introduced to the intervention

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<thead>
<tr>
<th>Participant responses to introduction to the intervention (grouped thematically)</th>
<th>Data reference</th>
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<tbody>
<tr>
<td><strong>Incredulity / enthusiasm</strong></td>
<td><em>I was totally surprised that the NHS was actually operating in this way...and whether it’s a freak, freak thing and some Tory is going to notice it and snatch it back, (laughs) ...</em>(Site2_IPC04)</td>
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<td><strong>Bewilderment (lack of understanding and confusion)</strong></td>
<td><em>And that’s probably me because I didn’t understand, and maybe that’s a point, that it needs, um ... clarifying a little bit more for, because I’m sure, I don’t know what age group this is, goes through [...] But it seemed to be so much up in the air [...] and I don’t remember anything</em> (Site1_IPC04)</td>
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<td><strong>Shifting of responsibility – empowerment for whose purpose?</strong></td>
<td><em>I was quite sceptical when the letter came, like, you know, oh, so are they palming us off to, you know, private insurance deals or whatever</em> (Site1_Carer 03_IPC15)</td>
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<td><strong>Lack of candidacy – why me?</strong></td>
<td><em>And so I don’t know how she knew I was, um, had a long-term illness, [...] whether names were given to, given to them from the surgery saying, ‘Oh, you know, maybe these people might fit...’</em> (Site1_IPC02)</td>
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<td><strong>Ethically questionable – who benefits?</strong></td>
<td><em>because I think it could easily be abused. I think, I think somebody could sort of use it as a means of getting everything and anything they wanted.</em> (Site1_IPC12)</td>
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<td><strong>Self rationing /responsible health citizenship</strong></td>
<td><em>Had the medical profession got fed up with me, had I been there too many times? Am I being a nuisance [...] being shifted sideways?</em> (Site1_IPC14)</td>
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People as theorists – internalised discourses

• Responsible individualism vs ‘empowerment’ (whose benefit? Salmon, 2003)

• Capacity/willingness to engage in a holistic health discourse (Naldemirci et al 2016, Schaeff et al, 2017)

• Candidacy (Dixon Woods, 2006)

Self rationing/acquiescence and/or Resistance/scepticism
Model of engagement with IPC programme

Context

Resource

Mechanism

Response/Reaction

Outcome

Pawson and Tilly, 1997; Dalkin et al., 2015; Jagosh, 2017

Participation

Engagement with new model (narrative development)

Non Participation

Lack of consent to enter programme

Partial Participation

Scepticism; Resistance active/passive to goals of programme

Social Network

Practitioner

Person

Wider social, economic, policy environment

Intervention theory

Organisational Culture

Pawson and Tilly, 1997; Dalkin et al., 2015; Jagosh, 2017
Model of engagement with IPC programme

CONTEXT

- Wider social, economic, policy environment
- Intervention theory
- Person
- Social Network
- Practitioner
- Organisational Culture

MECHANISM

- RESOURCE
- RESPONSE/REACTION

OUTCOME

- PARTICIPATION
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- NON PARTICIPATION
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**Context**
- Wider social, economic, policy environment
- Interventions theory
- Organisational culture
- Social network
- Practitioner

**Mechanism**
- Engagement with goals of programme
- Lack of consent to enter programme
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**Outcome**
- Participation
- Non participation
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**Resource**

**Response/Reaction**

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- Engagement with goals of programme
- Lack of consent to enter programme
- Scepticism; Resistance active/passive to goals of programme
Example – Janine, Woman, aged 53, not working, Has Fibromyalgia, depression, obesity, osteoarthritis, asthma living with husband, Jeff, who has osteoarthritis and fatigue. IPC practitioner is their community matron (Lyn) who is part of a multi-disciplinary team delivering IPC.

INT - And did you feel you were able to say about your life in general to them about what you really thought about?

Janine – I couldn’t talk to them like that. Um

Jeff – I do.

Janine – You normally talk. But with Lyn I can, I can say anything to her and she knows, she always picks up and knows what I’m on about. [Laughs] Bless her.
If a practitioner is known to a person and their social network and trusted and enables shared understanding and expectations of the intervention then a person will engage with the first step of P3C

Example – Janine, Woman, aged 53, not working, Has Fibromyalgia, depression, obesity, osteoarthritis, asthma living with husband who has osteoarthritis and fatigue. IPC practitioner is their community matron who is part of a multi-disciplinary team delivering IPC.

**Known practitioner** (pre-existing level of trust between person/carer and practitioner)

- Respectful, friendly and empathetic practitioners
- Relationship and trust building (Length of visit, frequent visits)
- Coordination with other practitioners

**Context**

- Respectful, friendly and empathetic practitioners
- Relationship and trust building (Length of visit, frequent visits)
- Coordination with other practitioners

**Resource**

- (Increase in) Trust
- Person/carer feels heard and respected

**Response/Reaction**

**Mechanism**

**Outcome**

PARTICIPATION Engagement with new model (narrative development, holistic model of health, closure)
If the practitioners are not known to the person, trusted relationships need to be built. A co-production group at Site 1 was one way of building relationships with practitioners and other participants and led to further engagement with the intervention.

Example – John, Man, aged 72, partially retired photographer. Has Parkinson’s, self-reported low mood. Living with wife (Jilly) who describes herself as his ‘proper upper’. IPC practitioners were not known to them pre-intervention.

Co-production group initiated by participants after meeting at an IPC process evaluation session. Group facilitated by IPC practitioners.

Jilly: [Laughs] But I'm not completely not sceptical [sic] until, you know, the first few meetings and then you think, 'OK', you know, ‘there's something here’, you know, ‘that could really help us’ INT – OK, so the meetings ...

Jilly – Did help. **Definitely, the face-to-face, you know** ... (Site1_Carer 03_IPC15)

John – I thought it was good that, um, that meeting yesterday. INT – Yeah. In what way?

John – Well, um ... it cleared up a few things and it's nice to see other people. I like people. (Site1_IPC15)
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Co-production group
- Information gathering/sharing
- Sharing experiences
- Relationship building with practitioners/peers

 RESOURCE

Co-production group
- Information gathering/sharing
- Sharing experiences
- Relationship building with practitioners/peers

RESPONSE/REACTION

• Trust
• Shared understanding of purpose of the programme
• Person/family and professional expectations of person centred care identified and understood
• Candidacy to programme

OUTCOME

PARTICIPATION
Engagement with new model (narrative development, holistic model of health, disclosure)

CONTEXT

Person context
- Unfamiliar practitioners
- Lack of trust
- Sceptical (wider political motives)

Partner
- Unfamiliar practitioners
- Lack of trust
- Sceptical (wider political motives)

Person/carer
- Mutual trust

Practitioner context
- Person unfamiliar
- Competency, knowledge, motivation
- Engagement, Enthusiasm
- Support from team
- Coordination with team
Practitioner creative mechanisms to build trust and shared understanding

- Competence and motivation (passionate, creative practitioners)
- Personal qualities (empathetic, respectful, friendly)
- **Relationship building (Longer visits, multiple visits, trust built over time)**
- Multiple information formats (letter, phone call, interaction with different practitioners in team)
- Coordination with other practitioners
- **Building social networks (co-production group and practitioners)**
Terms of engagement – emerging theory

- If practitioners, participants and carers/social network build trust through relationships (or have an existing relationship of trust with a practitioner) and have shared understanding and expectations of the purpose of the programme AND when the participant and their network believe they are candidates for the programme, then there is more likely to be engagement with the new model and participation in development of an authentic narrative.
Conclusions – are theories of person centredness falling through the gaps?

- Incoherence in programme theories and conflict with dominant narratives (e.g., neo liberalism) perceived by participants: overlapping concepts of empowerment, self management, activation, engagement, control, enablement, choice (Fumagalli et al, 2016). ‘Empowerment’ is not synonymous with ‘self-management’ or levels of ‘activation’ (Foucault, 1982).

- Engagement as an essential component of empowerment (Fumagalli et al, 2016).

- Terms of engagement (including candidacy, Dixon Woods, 2006) are necessary as a pre-context for entering into a P3C programme – require practitioner/participant/social network creativity and adaptation to context (Naldemirci, 2016).

- ‘Relational management of health’ is a better conceptual label than ‘self management’ in which all contributions are explicit and acknowledged (cf. Nolan 2001 ‘relationship centred care’).

- Ethics/risks of ‘empowerment’/self management with elderly complex people (Gibert, 2017)
Practice implications – the individual in a network

- Unless people’s context and individual circumstances are understood then an ‘authentic’ narrative is unlikely
- Unless a trusting relationship is built with practitioners then pre context for narrative development will not occur
- Shared understanding, expectations and candidacy are also necessary early responses and create a context for later P3C work
- Narrative is co-constructed with social network, practitioners and possibly peer groups
- Practitioner training, as well as their individual creativity is important to facilitate these contingencies


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