



# Data Sharing as currency in the Care Economy: A case study of an emerging care economy in Adult Social Care

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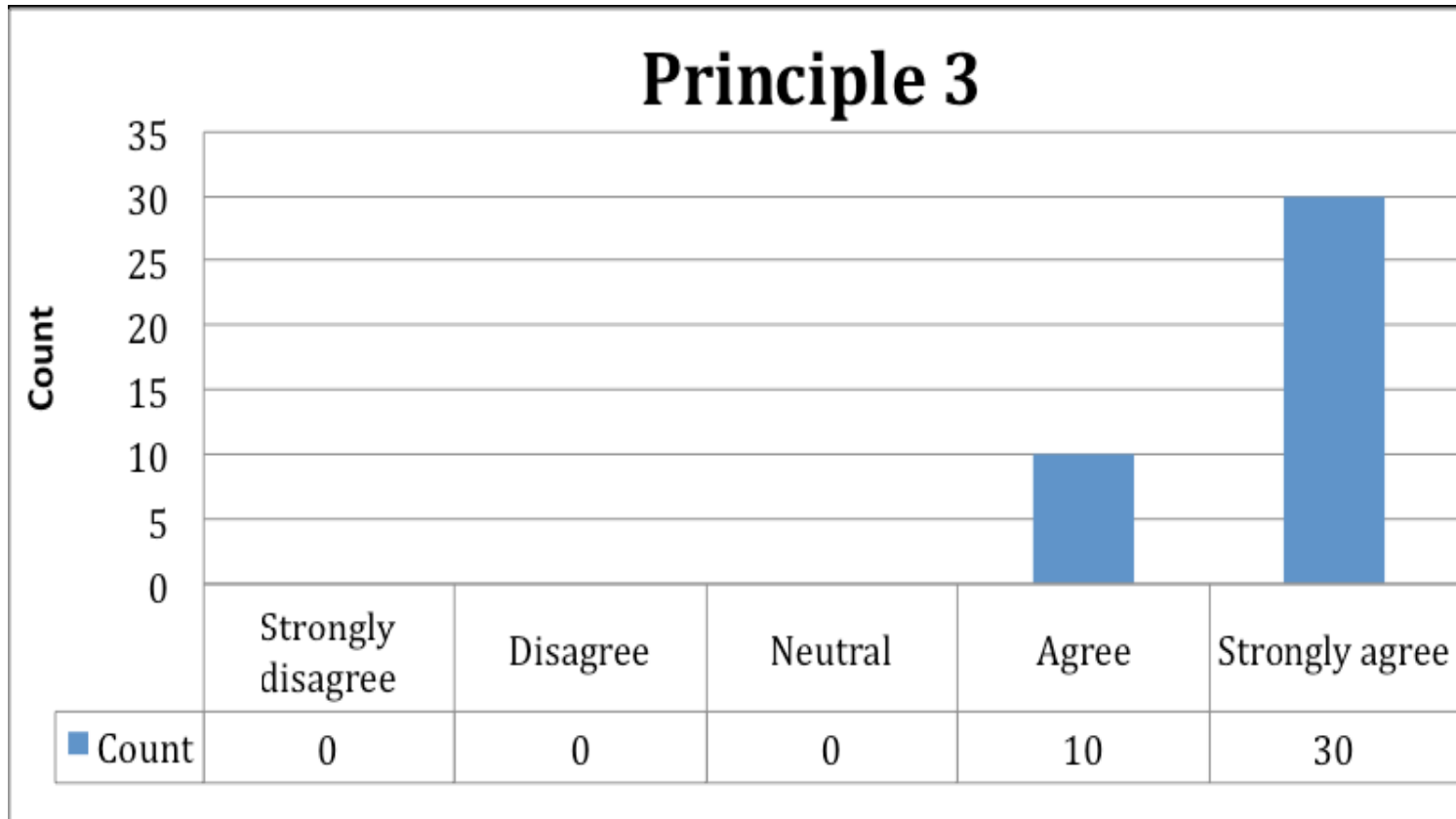
# Why are we here?

- Naked patients?
- Or better dressed empowered citizens...
- We need to co-ordinate our communities better in order to provide better co-ordination for the people we care for

# The recent review...

- Demographic change will require increased information sharing to manage care: it should be given higher priority in the information strategies of both health and social care sectors.
- At a strategic level, it would be helpful to have a high level mechanism for the DH, DCSF and NHS Management Boards to share information about their plans and strategies for information systems.
- Options for future of the National Programme for IT should address how information-sharing between health and social care will be taken forward as a mainstream facet of any future work programme.
- The Department of Health should issue guidance that supports local government in developing nationally consistent data standards and definitions across all 150 councils with adult social care responsibilities.
- The Department of Health's role in relation to leadership and resourcing of information strategy work should be reviewed – perhaps in the context of the 'Putting People First' concordat.
  
- Independent Review of NHS and Social Care IT chaired by (Sir?) Glyn Hayes

Appropriate information sharing is essential to the efficient provision of safe, effective care, both for the individual patient and to the wider population of patients.



# Extracts from RCGP/CfH – Shared Record guidance

- “Developing models of information sharing and record systems to support these requirements have been **patchy**, and not uniformly led by common principles of clinical communication and governance.”
- “We recognised from the beginning that “information sharing” and the “shared electronic health record” are not synonymous and the focus of this work is the shared electronic health record.”
- From ***Informing shared clinical care*** Final report of the **Shared Record Professional Guidance project** RCGP/CfH 2009

# Everyone seems to be violently agreeing

- Lots of talk about how information sharing is very important
- But it needs to be governed
- Lots of talk about standards and markets and how they can shape the ICT
- Not that much about who is doing what in the market, how and to whose benefit or why they should or would get involved (BTW the governments theory is personalisation).
- That's all very well in practice...but where's the theory?

# Evidence but little theory-

## To share or not to share

- Information sharing is a human and social process, driven by professional decisions making, and underpinned by human values, and the application of ethical considerations.
- Technology supplies mechanisms for access to information or for its exchange, and can be used to reify the rules and requirements within the process but cannot replace the social interactivity required to ensure that data is shared appropriately.
- It's likely that the Customer Service relationship within the emerging Care Economy will be continue to be mediated (created, reviewed, ended) via particular forms of user/provider 'service transaction' (such as referral, assessment, care plan components, commissioning of service, etc).
- A service transaction of this sort forms a 'trade' (wherein sensitive/personal information is exchanged to enable delivery of a service, and the details of the transaction is recorded)
- Data/information becomes the currency exchanged in these transactions

# Context

- Data sharing across a care economy
- The impact and implications of Personalisation
- Your patient; my client (or carer) welfare recipient, service user...
- Is the implication of a Shared Record - our customer? –

# Transforming Adult Social Care

- Background to the case Study:
- Part of wider research looking at the issues underpinning the use of Information and IT in Social Care assessment.
- Focused on one, county based, Local Authority (initially both Children and Adult services, but moving to an Adult focus in the latter half of the study.)
- Data collected over three years, reflecting move from ‘traditional’ care delivery to initial steps into personalisation of services
- Researcher engaged in projects developing new IT tools to support assessment processes, but also looking at role of information in the support of practice.
- Case study reflects an organisation in transition – business processes and supporting systems still being developed as the requirements and implications of policy emerge.

# Transforming Adult Social Care

- Overall project addressing:
  - Re-engineering of business process (the customer journey)
  - Development of Resource (Budget) allocation system to determine personal budgets
  - Development of training materials to support new approaches
  - Moving assessment focus to outcomes, via self directed support exercising personal choice and control.
  - Challenges to established behavioural norms
- Integration with health seen as a later stage

# Transforming Adult Social Care

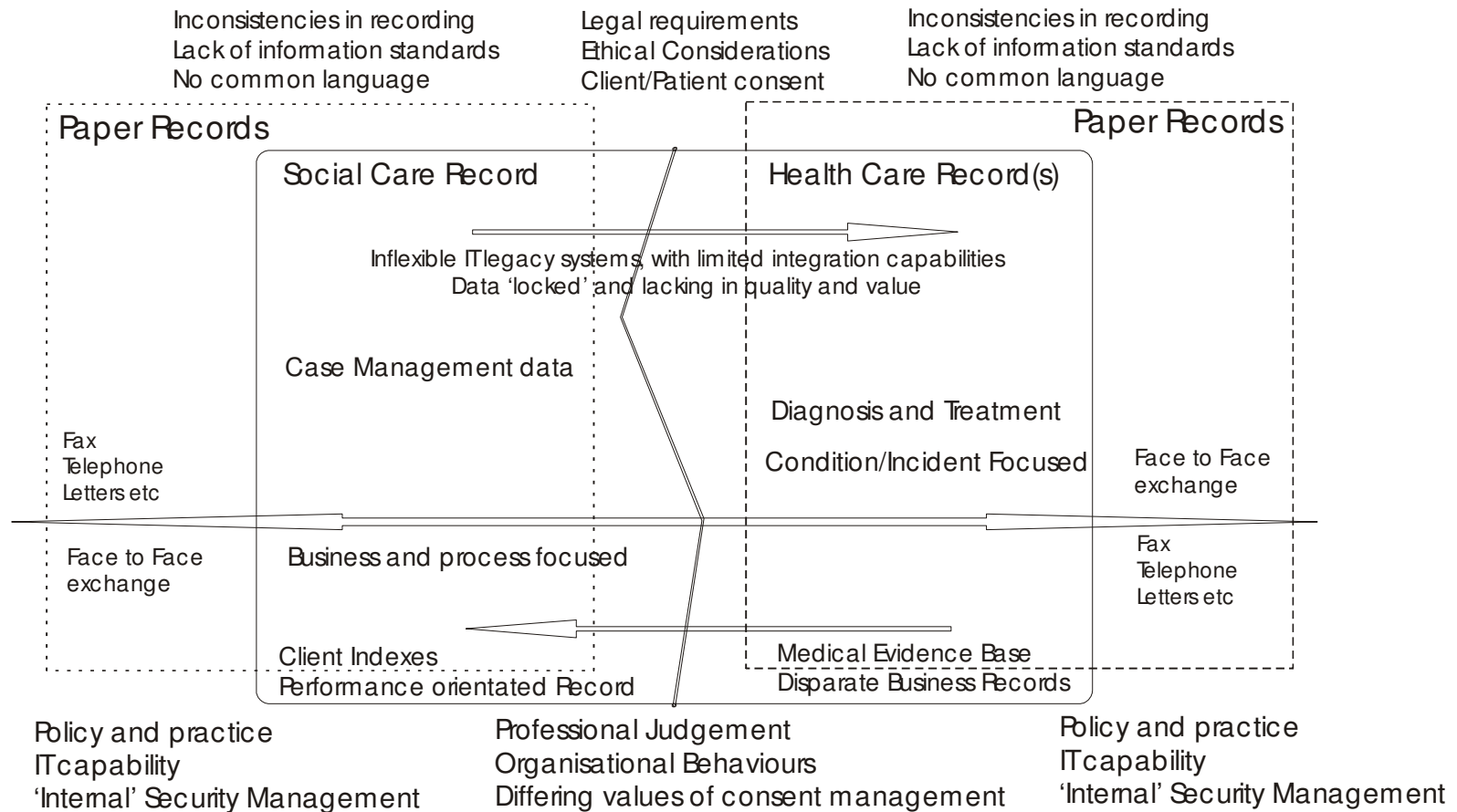
...it's a Herculean task, because the staff are so used to doing things in a very kind of prescriptive, service led way – and now we're asking them to do what they're trained to do ... and ... it's something a bit more demanding practice-wise. So, it's a huge task, but I think, yeah, we have started it.

...there's almost a kind of superstitious feeling that unless you've got a really ... you know, an assessment that's ten pages long ... something's not quite right.

(Project Manager, May 08)

# Structuration – a framework for analysis

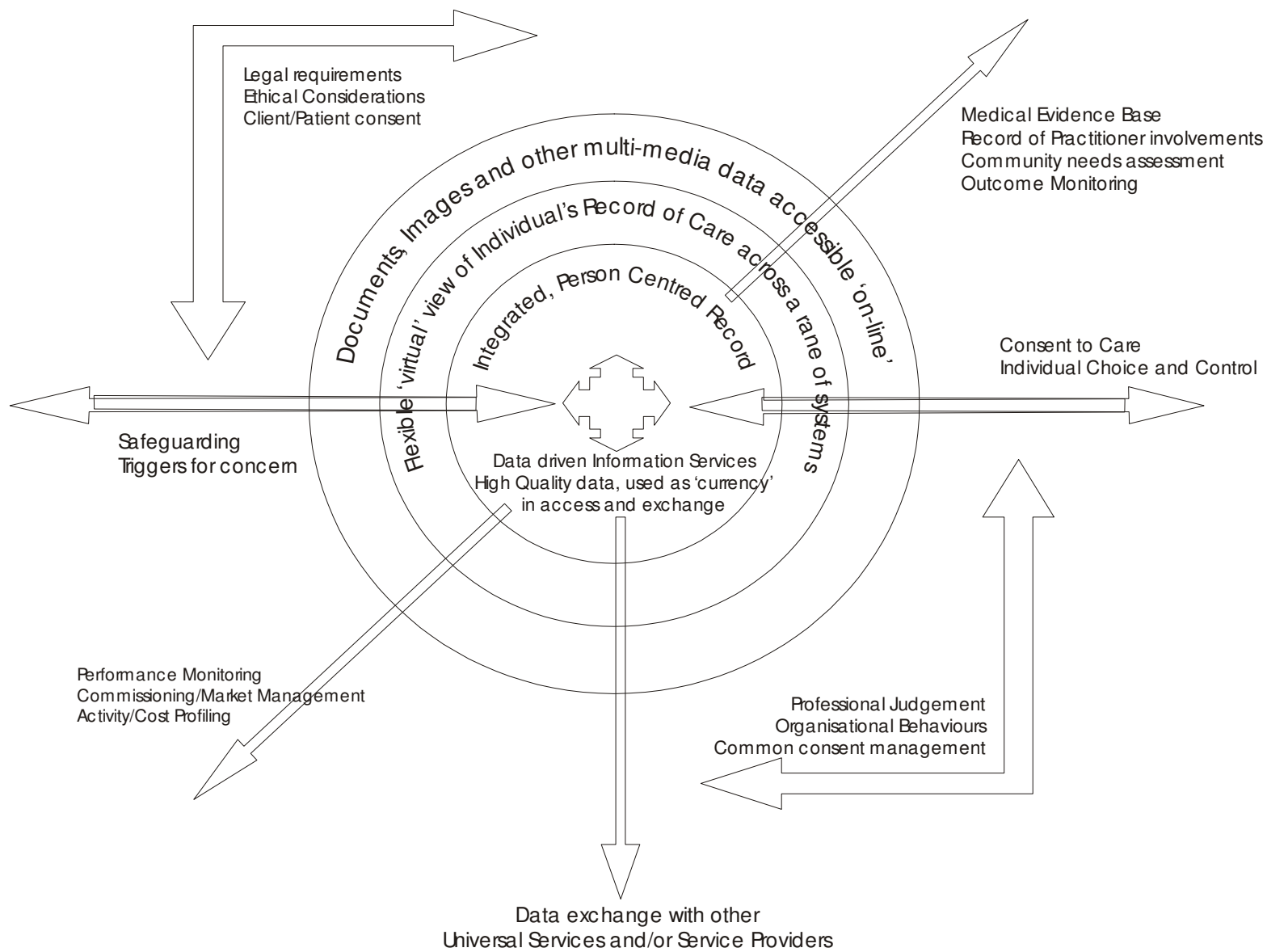
- The core argument of structuration theory is that social structure exists in the actions of human agents as they use existing structures and create new ones in the course of everyday life.
- *Structuration* is the process of putting structures into action.
- “structures are systems of ongoing action, being continuously produced and reproduced through time. The concept also emphasizes the ‘duality of structure: the mutual dependence of structure and agency (Giddens, 1979, pp 69-79).”



'Traditional' Information structures underpinning information sharing  
 between Health and Social Care

# Structuration components identified

Traditional Community Care	Structures (Rules and resources)	Modalities	Interactions
Signification	Policy, National and local Professional practice (theory and research)	Training Guidance Information/Knowledge base Practitioner Experience	Assessment practice
Legitimation	Law, duties and powers, social and professional values and standards Recording Standards	Eligibility criteria Targets Performance Monitoring	Assessment process  Assessment tools
Domination (control of resources)	Organisational arrangements, (eg budget management) formal procedures (internal and multi-agency) Service user consent	Service user (and carer) views Supervision Resource panels	Practitioner decision making, Authorisation, Service user agreement Data sharing



## Proposal for Information Structures underpinning Personalised Care Services

# Structuration components identified

New processes (structures in operational delivery)	Structures (Rules and resources)	Modalities	Interactions
Signification	Policy, National and local Professional practice (theory and research)	Training Guidance Information/Knowledge base	Supported Assessment (Transfer of Agency)
Legitimation	Self directed support directives (But eligibility still a constraint)	Eligibility criteria Targets Performance Monitoring	New Assessment process New Assessment (and other) tools
Domination (control of resources)	Customer choice Customer Consent Budget allocation (RAS)	RAS calculator Direct payments Access to Service Directories	Self directed support Risk Assessment Brokerage Advocacy Data sharing

# Transforming Adult Social Care

- ‘We’ve been so rigid and prescriptive for so many years that actually, staff have institutionalised. The (old) process has institutionalised them and stifled that creativity. ...we still need to work on those issues ... originally I said ‘why can’t we just change the tools?’ But you have to have the system changed to go with it, to have the ability to deliver.

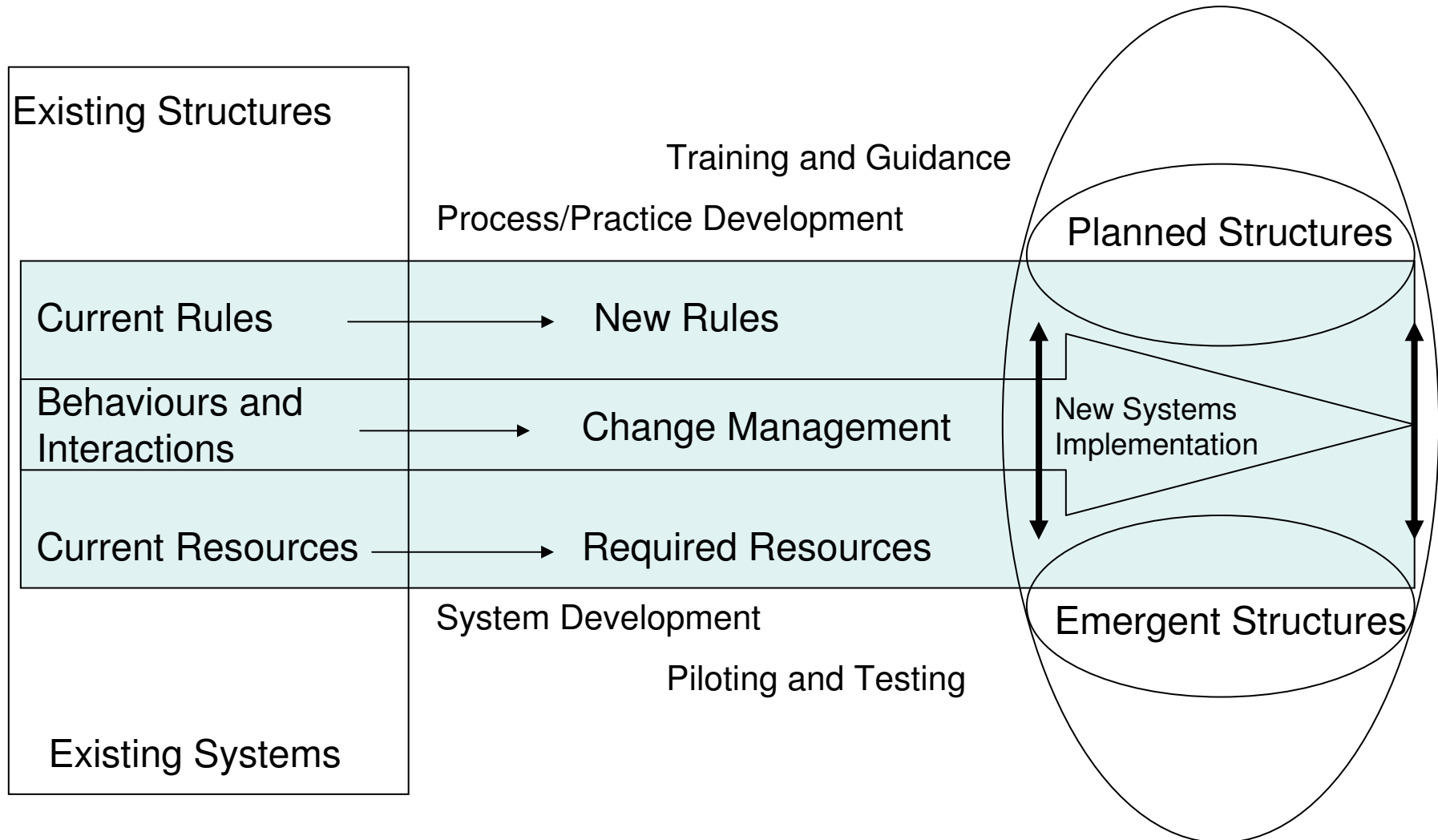
(Team manager, reflecting on phase one, Feb 09)

- ...we can understand why systems need to be in place – they actually have helped us focus our work ... the big shift is the culture change, not only from an individual’s perspective, (but) customers, the team, the organisation – and actually, I think, in the management of change we need a lot more consideration ...

(Practitioner, considering the impact of the project, Feb 09)

# Structuration Analysis

## A framework to support change



# In summary

- Personalisation promotes an expectation of wider choice and individual control, focusing on the person *as a customer* (limited though that is conceptually!!!)
- The structures that support the delivery of personalised, multi-agency care will be shaped, not just by the interaction between policy, process and tools, but also by the overlay of organisational culture, expectations of professional practice, and potentially tensioned policy directives with differing objectives and compliance requirements.
- Information sharing will provide the foundation for these structures, enabling the transactions of the care market and the wider care economy.