



Confidentiality Issues

User perspectives

Lessons from Learning Disabilities

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NCeSS Small Grant

- Project Aims
 - Specific focus
 - Demanding use cases
 - User analysis
 - Providers
 - Clients
 - Technical Feasibility
- Workshops
 - Confidentiality
 - User requirements
 - Technology



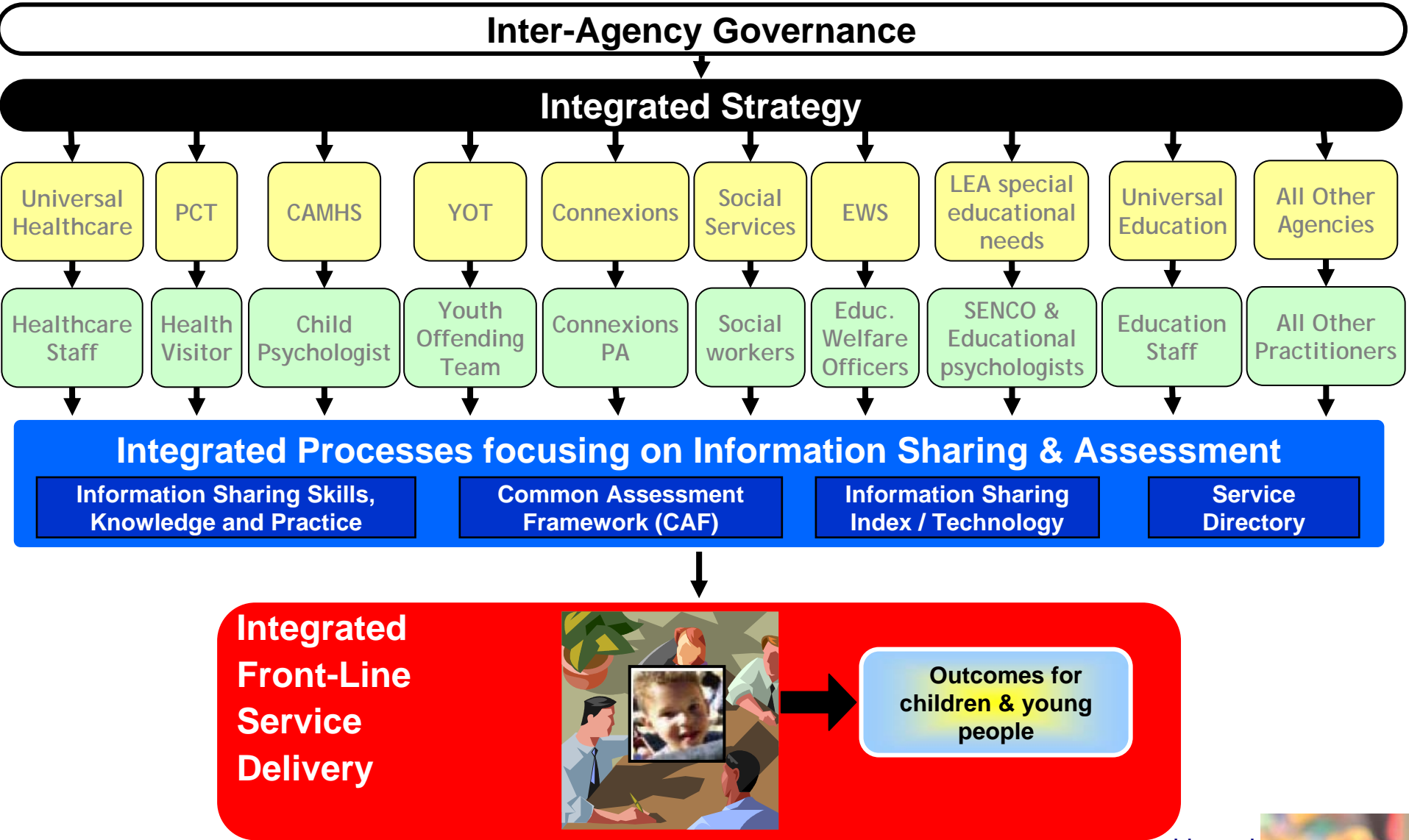


Key Issues

- Common requirements – generic issues but using a specific exemplar of learning disabilities
- Disparate actors - health, education, social services, academic, voluntary etc. with typical concerns
- Inconsistent and disperse data – can new technologies help?
- Specific focus on confidentiality concerns – the public good vs. the individual rights (especially when the individual may not be able to decide for themselves)

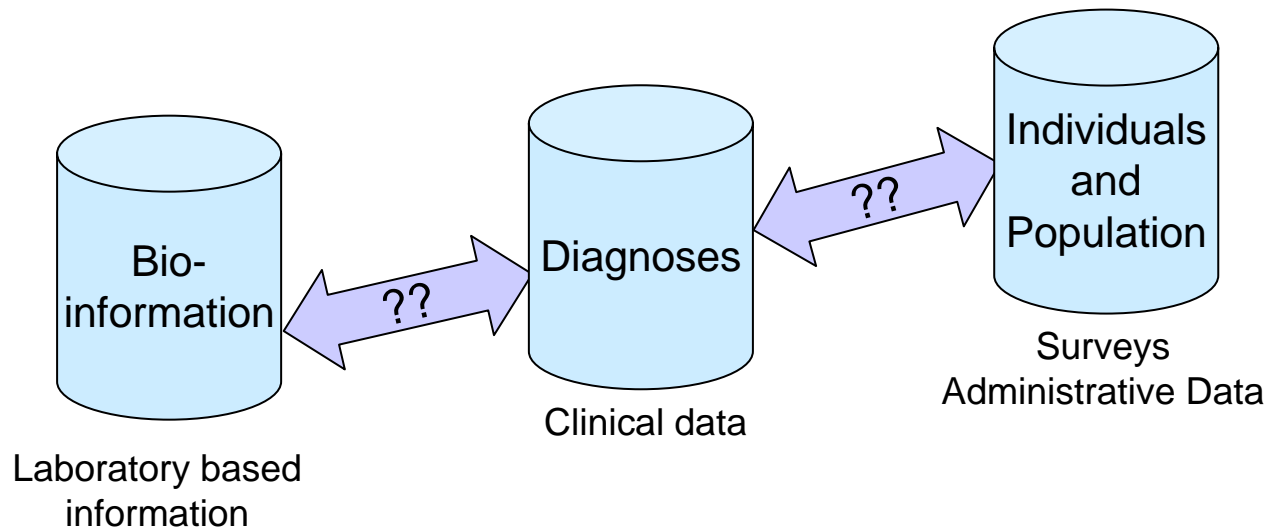


Future: Integrated Children's Services



Health Informatics Continuum

Linking within and between data silos



Users, barriers and solutions?





Use Cases

- Policy/Research Scenario
 - Seeking an overview/ understanding/ evaluation
 - Focus on aggregate information/ analysis/ presentation
- Service Scenario
 - Focus on the individual
 - Obtaining as complete a picture as possible of the care history and possibilities





Sources of Data/Information

- Trials (clinical)
- Surveys (national, local)
- Administrative records (health, social care, education)
- Classifications (coding)
- Textual information (notes, reports etc.)
- People (semantic)





Methodology

- Data confidentiality workshop
 - short presentations
 - computer-based “brainstorming” tools
 - All participants were *enabled* to respond to various key questions and then asked, in small teams, to group the main responses
 - whiteboard sessions
- Discussed the
 - Importance and benefits of sharing data
 - What worked well
 - What worked less well
 - Future directions
- Report summarises the discussions and findings of the workshop.





Participants

- Representatives from:
 - Learning disability service providers
 - Policy makers
 - Researchers
 - Experts in web technologies (Essex CC Ontology Engineer!)
 - Ethics boards
 - Patient and citizens' rights organisations
- Facilitators
 - Experts in qualitative analysis





Importance of Sharing Data

- Effective use of resources
 - Co-ordinate individual care
 - Understand what is happening
 - Review original policy objectives
 - Improving research opportunities
- Integration
 - Joined-up working
 - Policy improvements
 - Placing Learning Disabilities in a wider framework
- Improved participation by all stake-holders, especially end-users/beneficiaries
 - Promoting democracy
 - Access to information improves accountability
 - Equality
 - Consciousness Raising





Experiences

What works well

- Technical aspects

- Common standards and explicit protocols
- Semantic web technologies (web phase 2 ‘collaborations extend to computers ... capable of analysing all the data on the web – the content, links and transactions between people and computers)

- Data sources

- Freely available data is good, but
- ‘Because at the moment data is like an economic resource, control of it lies in the hands of a small number of people/organisations’





Experiences

What works well

- Communication
 - Good communication between trusted partners
 - Personal relationships
- Organisational structures
 - Strong project leadership
 - ‘Get the job done’
- LD-specific issues
 - Even more complex, trust between parties is a key issues
 - Consent and pragmatism



Experiences

What works less well

FOCUS

- Data concentrate on services
- Lack of data on outcomes and benefits
- Quality Controls
 - Can the data be trusted?
 - Lack of consistency – no standardised definitions, language, measures etc.
 - Lack of accuracy – outdated information, repetition, duplication
- Technical
 - How can data be identified and searched?
 - How can data be shared?
 - Can access be limited to those with permission?





Experiences

What works less well

- Legal

- Do individuals consent to their data being shared?
- Can different sources be linked?
- Are there safeguards against misuse?

- Access Control

- Who is allowed access?
- What is the application procedure?
- What authority oversees the system?





Conclusions

- Massive investments in technology, but in one sector
- Consistent coding and ontologies essential
- Most actors seem to send data around to trusted colleagues by CD
- More ad hoc collections seem to exist to 'get job done'
- Data protection technologies are too far away
- Views of professionals dominate over the patient, who may not be seen as partners
- Organisational hurdles are by far the biggest

