

Exploring GRID technologies for 'joined up' Learning Disabilities Data

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In the beginning...

- The National Centre for e-Social Science (NCeSS) - funded by the Economic and Social Research Council (ESRC) to investigate and promote the use of e-science to benefit social science research. (see <http://www.ncess.ac.uk>)
- ESRC / NCeSS Small Grants Scheme
- serendipity

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Background

- Typical issues for those with learning disabilities include the following:
 - A higher propensity to other physical and mental illnesses.
 - Reduced life expectancy in comparison with the general population.
 - Poorer access to medical services.
 - Over-representation in the prison population and amongst the homeless.
 - Poorer socio-economic circumstances, often due to costs of caring (including carers giving up work).
 - Higher unemployment.
 - 50-60% live at home with families putting strain on carers.

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Context

- Wanless II Report (2004)
- Public Health Sciences: Challenges And Opportunities (Public Health Sciences Working Group, 2004)
- NPfIT and SUS (Thorpe, 2004)

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NPfIT

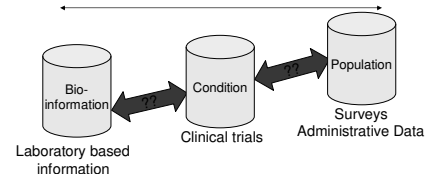
- The National Programme for IT (NPfIT) has been established as a means of driving forward the implementation of modern information systems and technology across the NHS.
- The programme is supported by a central Department of Health budget
- 10 year project starting 2003
- £2.3 billion for the three financial years 2003-2006
- contracts worth £6.2bn over project lifetime
- Plus £1bn 'local baseline IT expenditure'
- Aiming for ~ 4% total NHS budget (as per Wanless)

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Health Informatics Continuum

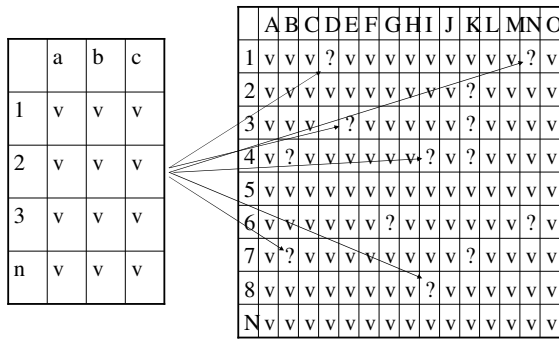
Research potential in linking bio-information, clinical / social care data and survey data

Thematic slices (e.g. Learning Disabilities))



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Research potential – ‘sparse matrix population’



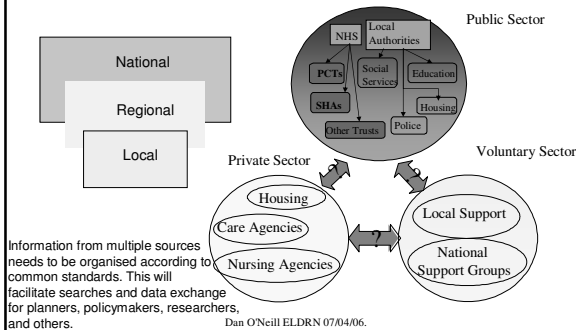
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The problem

- Learning disability as a multidisciplinary / multiagency enterprise
 - Multiple data sets with variable quality and structure
 - Multiple uses
- Learning disability as an area of social need
 - Health, education, housing, crime, employment
 - It is under-resourced and would benefit from a special focus from innovative IT developments.
 - The project has also been able to link in with the emerging Eastern Region Learning Disabilities Network at an opportune time.

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A Disparate Information Space



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The aims

- a pilot project that aims to assess the suitability of the latest e-science technologies for addressing the issues of health service policy and research
- The project focussed on three areas.
 - The existing information space.
 - The user requirements.
 - The technical feasibility.

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Methods

- Literature review
 - Technical
 - LD
- Networking (individuals & projects)
- Interviews with key informants
- Workshops
 - Mapping*
 - User requirements
 - Technical feasibility

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Navigation: [Home](#) [Group Members](#) [ToDo](#) [Data](#) [audit](#) [Literature](#) [Meetings](#) [Meeting Minutes](#) [Discussion](#) [Availability](#) [Confidentiality](#) [Workshop](#) [ESRC Proposal](#)

Welcome to the Learning Disabilities GRID Project. This forum is designed to help us keep track of the project, contribute ideas, information and comments.

Dear all,

Recent Changes to the Forum:

I have made some changes to the forum while trying to make it a bit more organised:

1. ToDo List is now organised by Project member.
2. 2 more areas have been added: Meeting Minutes (containing notes about each past meeting, as a log) and Discussion Area (for ideas, feedback, questions, well, discussion).
3. I have placed a Navigation Bar on the top of each page, so that the navigation within the forum can be more efficient. (The way it was before, if one wanted to go from, say, Project Members to ToDo, one had to go back to the Home page and then to ToDo).
4. Of course I haven't erased any content that was already there - however, I've moved some stuff around - e.g. some posts from the ToDo area have now been moved in the Discussion Area.

I hope you find all this useful - if you want anything else to be changed, or think that any of the above changes makes life harder rather than easier, just let me know and I will fix it.

John G.

For some introductory information about the nature of the project, please see the following:

- Original Project [abstract](#)
- This powerpoint file is the presentation that Simon gave at the Research Committee of the National Centre for e-social science on 23th Feb: [LDRN committee presentation.ppt](#)
- This pdf is the abstract (unashamedly 'stagnated from the proposal document') that went in at 16.59 on Tuesday 1st Feb, in response to the NCeSS call for the conference in Manchester in June: [LDRNmember Conference abstract 1.pdf](#)
- [Meeting Minutes 1](#)
- [Confidentiality Symposium in Manchester 3 May](#) <http://www.sccc.ac.uk/capri/symposium/> - we should do ours after this.

Workshop 1: Barriers to access and sharing

- Social / organisational
 - Lack of knowledge by potential users of available resources
 - Ignorance of appropriate technologies
 - Poor metadata usage
 - Neglect
 - Hoarding / secrecy
 - Lack of incentives to share
 - Confidentiality concerns
- Technical
 - Different metadata standards
 - No consistent ontologies (content and format)
 - Limited text search
 - Heterogeneous formats
 - System interoperability
 - Poor data exchange / conversion tools

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Workshop 2 participants

- OECD - DDD project
- Essex County Council
- Colchester Primary Care Trust
- The Northeast Essex Inclusive Communication Project
- SAFE
- Clinician / practitioner viewpoints

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Workshop 2: User requirements

- **Integration**
 - **Despite massive investment in the NpFIT, there are still no plans in the short - medium term for integrating health and social care data**
- **Efficiency**
 - **Duplication of effort, increased risk of errors and inconsistencies**
- **Customised Searching and Access**
 - **Access and use should reflect the needs of the user – 'top-down' vs 'bottom-up'**
- **Security**
 - **Good access control is vital to success of system**

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Workshop 3 participants

- MIAKT3
 - Medical Imaging and Advanced Knowledge Technologies, funded by the Engineering and Physical Sciences Research Council (EPSRC)
- CancerGrid4 (MRC funded project)
- DIP5
 - Data, Information, and Process Integration with Semantic Web Services, funded by the European Union
- CLEF6
 - Clinical e-Science Framework, funded by the MRC
- Essex Uni Computer Scientists

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Workshop 3: Technical perspectives

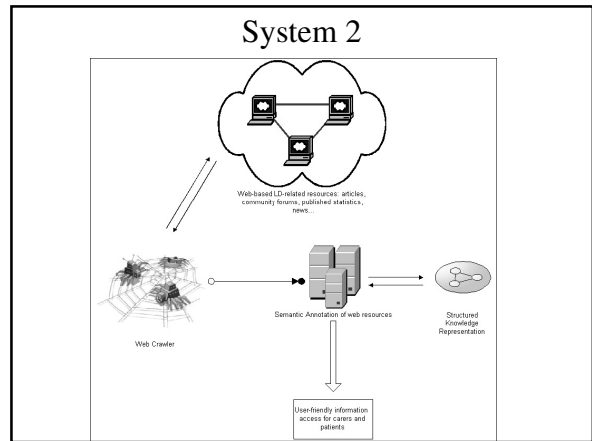
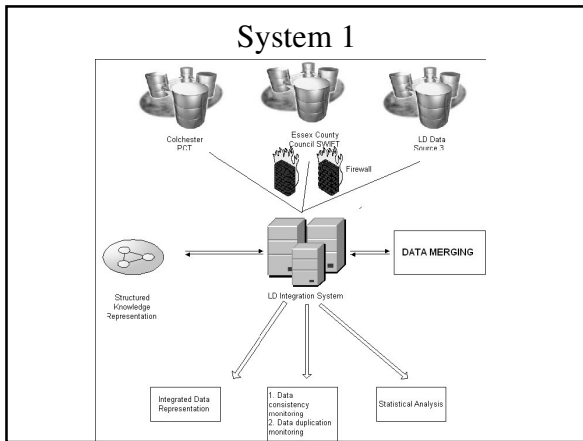
- Focus on 2 'use cases'
 - Policy scenario
 - High level overview for planning or research
 - Service scenario
 - Focus on obtaining information to support the individual

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system design recommendations

- adopt existing platforms that have been shown to work well in other projects such as CLEF, MIAKT and DIP
- develop reusable data sources
- use open standards
- have a particular focus on security and confidentiality.

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Conclusions

- Deficiencies in integration and accessibility of information lead to inefficient working practices and sub-optimal services for people with learning disabilities
- it is unlikely that such integration will ever be achieved by a 'single-system solution'
- semantic web technology might offer a realistic alternative, and enable far better use to be made of existing data
- Implementation will need to address social / organisational barriers as much as technical issues

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Next steps

- Development of working prototype?
- Integration of data from National LD Survey with primary care data?
- Application / generalisation of project to other areas eg CAMHS?

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Publications and resources

- Project webpage:
<http://www.essex.ac.uk/hhs/research/Projects/LDgrid.htm>
- Workshop 1: Confidentiality and Ethical Issues in the Wider Usage of Clinical and Administrative Data
<http://www.ncess.ac.uk/events/agenda/confidentiality/index.shtml>
- e-mail doneila@essex.ac.uk

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'Challenges'

- Funding
- Change of personnel
- Hijackers
- Overheads

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