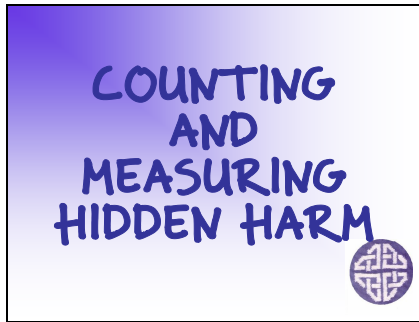


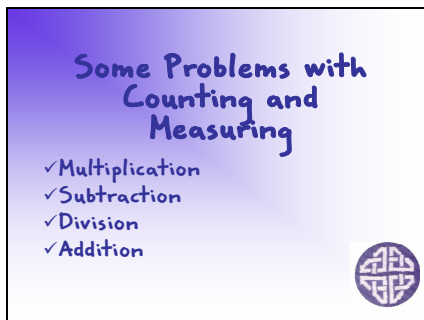
Counting and Measuring Hidden Harm

The presentation slides and notes from a conference address for Sandwell Local Safeguarding Children Board by [Allan Norman](#), 27th February 2007. It critically explores legal, ethical and practical issues around the growth in databases, with particular reference to the [Hidden Harm agenda](#) (about children of problem drug users) and to the forthcoming Childrens' Information Sharing Index



Listen to the following recommendations from the Hidden Harm report:

1. All drug treatment agencies should record an agreed minimum consistent set of data about the children of clients presenting to them.
2. Whether a client or patient has dependent children and where they are living should be included as standard elements in... the Drug Misuse Databases...
3. Problem drug or alcohol use by pregnant women should be routinely recorded at the antenatal clinic and these data linked...
8. The Department of Health and the devolved executives should ensure that all maternity units and social service children and family teams routinely record problem drug or alcohol use by a pregnant mother or a child's parents...
9. The National Treatment Agency and the devolved executives should ensure that all specialist drug and alcohol services ask about and record the number, age and whereabouts of all their clients' children...



As will be shown later, these are just some of the recommendations in the Hidden Harm report that we should count, measure and record.


These recommendations are fully consistent with the government's agenda expressed in Every Child Matters, and with the Children's Database and other measures found within the Children Act 2004 to give effect to the Every Child Matters agenda. They are also consistent with the calls we have heard this morning, for 'better data sets', and the explanations that the government in England at least sees the implementation of the Hidden Harm agenda as merely part of its wider Every Child Matters agenda.

This presentation is critical of the calls to count measure and record, in particular insofar as it relates to the Childrens' Information Sharing Index is concerned. It argues each of the following:

- It argues that excessive counting and measuring is dysfunctional;
- It argues that there are serious ethical concerns with a predilection to count and measure;
- It argues that there are serious legal concerns with the proposed database developments on the horizon.

Multiplication



The amount of data we hold is growing exponentially, as are the number of databases, indices, and systems for recording it.



The amount of data we hold is multiplying rapidly. So are the number of databases.

Multiplication

According to a paper published by the Information Commissioner in November 2006, "these are the major or innovative databases which collect (or soon will collect) information about children in England..."

An analysis of the recent growth in databases is included in the conference CD, but this summary is drawn from the Information Commissioner. For those not familiar with the Information Commissioner, this is a government official with responsibility for both Data Protection and Freedom of Information laws.


Here are the recent or forthcoming databases identified:

- ❖ Information Sharing Index (IS). To be introduced by 2008.
- ❖ Integrated Children's System (ICS). Proposed.
- ❖ National Pupil Database (NPD).
- ❖ RAISEonline (Reporting and Analysis for Improvement through School self-Evaluation). To replace similar existing system.
- ❖ "Lost pupil" databases
- ❖ ASSET
- ❖ ONSET. Currently at pilot stage.
- ❖ RYOGENS
- ❖ National Register of Unaccompanied Children (NRUC)
- ❖ NOTIFY
- ❖ MERLIN

Subtraction

Counting and measuring takes away time and resources from the delivery of front line services:



- ✓Resources
- ✓Time



Subtraction

The cost of the ICS alone is estimated at £224 million initially and £41m ongoing.

Action on Rights for Children observes:

That's peanuts compared to the cost of the ID card system, which recent estimates have put at approaching £18bn.

ARCH is a campaigning group on children's rights. They have a lot to say about the ICS. This is what they have to say about cost.


"8. The government says that it will cost £224m to set up the IS Index, and another £41m per year to run it. This is a major database project and, so far, all of the government's major IT projects have cost far more than was predicted. The £41m running costs appear very optimistic: this amounts to £270,000 per local authority. Bearing in mind the extra staff that will be needed, the training costs whenever a new practitioner is given access, the system maintenance and upgrade costs, it is difficult to see how it will only cost £41m per year. Will the additional costs have to be borne by local councils?

9. Local authorities have to pay for the eCAF system themselves. They also have to pay for another new system: the Integrated Children's System (ICS), a database that will store every child's social services record. The government's own Society of Information Technology Management estimates that installing an ICS system will cost each local authority £1m and that government grants offered to local authorities are only a fraction of the true cost. Local authorities are meant to install eCAF and ICS without increasing council tax, which means that other services have to be cut.

10. We believe it would be better to spend all of this money on services."

Division

The government has an agenda of secondary prevention. That is, it is focussing preventative services on targeted groups, including those seen as at risk of "hidden harm".




Primary prevention is a term used for universally available preventative services. Secondary prevention is targeted. The government's agenda involves division of children into those deemed to be "at risk" on whom services will be targeted, and others, who will not receive such services. Which begs the question, "At risk of what?"

Addition

The secondary intervention agenda has added to the meaning of, and therefore the number of people considered to be, "at risk":

- ✓ At risk of significant harm
- ✓ At risk of social exclusion
- ✓ At risk of anti social behaviour and crime




Addition

The Information Commissioner once again:

"Data protection should never be used as an excuse for failure to protect a child from a real risk of harm..."

Data protection issues may be less clear cut where the concerns focus on the welfare of children, rather than their protection. Child protection and child welfare are not the same thing. Child welfare is a much broader category.



The words before and after this quote:

"It is important to re-state that data protection law never stands in the way of using or sharing personal information – about the child and sometimes about others - where a real need exists. Harming children through abuse or neglect is criminal activity. Data protection law recognises the importance of preventing and detecting crime and pursuing offenders. This must be especially important where children are the victims.


Data protection should never be used as an excuse for failure to protect a child from a real risk of harm.

Data protection issues may be less clear-cut where the concerns focus on the welfare of children, rather than their protection. Child protection and child welfare are not the same thing. Child welfare is a much broader category - referring to children who are poor, or unhappy, or living in unsatisfactory neighbourhoods, or at risk in some other way of not growing up into happy adults with a reasonable chance to fulfil their potential. While child protection deals with a relatively small number of children – estimated to be around 50,000 in England - child welfare concerns may exist for three to four million.

The *Every Child Matters* agenda extends social care from protection to welfare. Although there are overlaps, this shift means that substantially more information will be collected and shared about substantially more children for different reasons. These different purposes raise different considerations from a data protection perspective. It is important that approaches used in the context of protection are not assumed to be transferable to the welfare context."

Addition


"...The *Every Child Matters* agenda extends social care from protection to welfare... These different purposes raise different considerations from a data protection perspective. It is important that approaches used in the context of protection are not assumed to be transferable to the welfare context..."



In summary, while the law is quite clear that consent is not required, and confidentiality can be broken, to protect a child from harm, it is rather less clear that data protection law offers any alternative to informed consent in respect of maintaining and sharing data and targeting services at those deemed at risk of social exclusion or anti-social behaviour.

Problems of secondary prevention

- ✓ Limits on intervention
- ✓ Labelling theory, false positives and negatives
- ✓ Information surplus to requirements



Limits on intervention:

"There are three key criteria to judge a screening programme against: predictive accuracy, treatability, and the level of damaging effects"

Munro E. (2007) 'Confidentiality in a Preventive Child Welfare System' *Ethics and Social Welfare*, 1, 1



"While there is an obvious attraction to the idea that we are able to predict, intervene, and so prevent serious social problems, the introduction of a screening programme for a social problem needs to be measured against the same scientific criteria as screening for medical problems, such as screening for cervical cancer. There are three key criteria to judge a screening programme against: predictive accuracy, treatability, and the level of damaging effects."

Labelling theory, false positives and negatives

"Research into the continuity of anti social behaviour shows substantial flows out of as well as in to the pool of children who develop chronic conduct problems. This demonstrates the dangers of assuming that anti social five-year olds are the criminals or drug abusers of tomorrow, as well as for highlighting the undoubted opportunities that exist for prevention."

'Support from the Start: working with young children and their families to reduce the risks of crime and anti social behaviour', C Sutton, D Utting, D Farrington, Home Office Research Brief RB924 (March 2005)



There is a particular significance to the fact that this statement comes from Professor Farrington: his 2006 research is relied on heavily by the government to justify targeted intervention. The primary/secondary intervention distinction is his – but he comes down in favour of primary intervention, because he does not accept that prediction is sufficiently accurate to justify targeted services – as this quotation shows.

Information surplus to requirements

"Increasing the amount of poor quality data available will lead to more errors, and out of context information can easily cause risk averse staff to panic, with serious consequences. There are also institutional and professional risks. US information sharing pilots have in many cases shown negative outcomes, because of the diffusion of responsibility."

'Children's Databases – Safety and Privacy', Foundation for Information Policy Research (2006)



Some of the problems of too much information are shown to be:

- ❖ Obscuring significant data;
- ❖ Out-of-date information;
- ❖ Inaccurate information;
- ❖ Difficulties interpreting significance;
- ❖ Complacency that the record is the solution;
- ❖ Lack of clarity as to responsibility.

This is what comes before and after the extract shown:

"Our fourth bundle concerns the actual harm that sharing can do. Government documentation and guidance is mostly unbalanced in that it ignores the dark side; it pays little heed to family values, therapeutic effectiveness, trust and privacy. By failing to respect the users of the social-care system, it risks deepening rather than ameliorating social exclusion. There is specific harm: in a disturbing recent case, a nine-year-old was wrongly taken into care after social workers misunderstood medical information. Increasing the amount of poor-quality data available will lead to more errors, and out-of-context information can easily cause risk-averse staff to panic, with serious consequences. There are also institutional and professional risks. US information-sharing pilots have in many cases shown negative outcomes, because of the diffusion of responsibility; and recently, professional disquiet in the UK has led to the 'Social Work Manifesto' whose authors object to having to "collude with youth justice policies which demonize young people".¹ Even if one does not share this radical view, there are certainly growing problems of recruitment and retention within the profession."

¹ 'Social Work – A Profession Worth Fighting For?', Chris Jones, Iain Ferguson, Michael Lavalette, Laura Penketh, at <http://www.liv.ac.uk/~swfuture/>

Positive/Negative


The purpose of recording data may be subverted by the process of doing so. Research evidence suggests that children will choose not to share their concerns and worries where they do not trust the officials not to further share the information.



Positive/Negative

Children's Rights Alliance for England


'Children and young people talk about information sharing'



Positive/Negative


'I think it's about trust: the views of young people on information sharing'

Office of the Children's Commissioner
September 2006



Memory Plus

The established Caldicott principles on information sharing, in particular principles 2, 3 and 4 emphasise necessity as the basis for information sharing.



Extract from page 4 of the document:

"There was a great deal of discussion about trust and confidentiality – and a strong feeling that children and young people need adults in their lives that they can trust and talk to in confidence. There was concern that if children thought adults were going to share information with other people, they would stop confiding in adults altogether. They believed that adults ought to be able to sort out difficulties with children and young people without having to breach their confidence.

"I think the people who are passing information need to consider the consequences of what will happen if they disrespect the child's wishes...like the child's not going to confide in them anymore or trust them. Obviously that's going to be bad if they're in a situation where they're in danger or they're self harming...and then they've got no one to turn to because they don't trust anyone..." (17-year-old female) "

Extract from page 28 of the document – the words that gave their name to the report:


"I think it's about trust, trust is an important thing especially between children and adults, the communication between children and adults isn't good these days, partly because it's based on trust, if there's no trust there, they aint going to tell you nothing. If you break that trust and you do tell someone else next time you have another situation like that, they aint going to tell no one and it could have more serious consequences than what it started out as.

Female, 15 years old, Youth support centre, Midlands"

In my experience, the Caldicott principles emanating from the Caldicott Report, and Caldicott Guardians are well established in health services. They should, by now, be equally embedded in local authority social work practice, but this appears not to be the case.

Memory Plus

- ✓ Don't use personally identifiable information unless it is absolutely necessary.
- ✓ Use the minimum necessary personally identifiable information.
- ✓ Access to personally identifiable information should be on a strict need to know basis.



Notice that the emphasis is on:

Necessity rather than desirability
 Minimum rather than maximum
 Privacy rather than freedom of information

Memory plus?


Well, to my mind, Caldicott correctly reflects the law, which effectively prohibits the processing of unnecessary information.

How is that consistent with automatic record keeping and information sharing?

Let's look in more detail at the law relevant to the processing of data.

Legislation

- ✓ European Law.
- ✓ Human Rights Law
- ✓ Domestic Law



Both European law and Human Rights law can be considered 'overarching law'. That is, they are sources of law having a higher authority than Parliament, in that Parliament is bound (at least while the United Kingdom remains part of the EC and signed up to the European Convention on Human Rights) to legislate consistently with these forms of authority.

Legislation

The source of our current data protection law is EC directive 95/46/EC. Domestic law cannot be amended in such a way as to make it incompatible with the European Directive.



Legislation

Article 8 of the ECHR provides a right to respect for private life, which is established as including the processing of personal data. Domestic legislation cannot be amended in such a way as to make it incompatible with human rights.



Legislation

The centre piece of the Data Protection Act is the eight data protection principles.

- ✓ Principle 1 – fair and lawful processing



Fair and lawful also requires that any processing is in accordance with a list of authorised grounds. There is one list for non-sensitive information, and another for sensitive information.

Informed consent can make processing fair and lawful. Obviously, social work does not always act on the basis of consent, hitherto the pattern has been that the coercive or controlling functions of social work have been without consent, but relied instead on “functions of a public nature”; “protecting vital interests” or “prevention of crime”.

It seems probable that in the future, consent will be bypassed not only for coercive or controlling functions, but also for welfare functions. Given the observations about Article 8 (which is a qualified right, but qualified by necessity) there will be inevitable challenges to this.

Legislation

- ✓ Principle 2 – Specified and lawful purpose
- ✓ Principle 3 – Adequate, relevant and not excessive
- ✓ Principle 4 – Accurate and up to date
- ✓ Principle 5 – Not kept for longer than necessary
- ✓ Principle 6 – In accordance with the rights of the subject
- ✓ Principle 7 – Protections against unauthorised disclosure



Note these principles are additional to principle 1. If you circumvent principle 1 by arguing that it has become a statutory function to process into a database (called ‘statutory gateways’), you still have to comply with principles 2-8.

With some of them, the problems are that it makes maintaining the database onerous – principles 4 and 5, for example, will require continual monitoring.

With others, the problems are potentially making the database unlawful – principles 3, 5 and 6 are examples.

Code of Ethics

“4.1.4 Informed Consent.

Social workers will not act without the informed consent of service users, unless required by law to protect that person or another from risk of serious harm...



BASW Code of Ethics will not accept a ‘statutory gateway’. It says explicitly that all non-coercive functions require consent.

Code of Ethics


...where the law vests the power of consent in respect of a child in the parent or guardian, this in no way diminishes the social worker’s duty to ascertain and respect the child’s wishes and feelings...



Code of Ethics



4.1.7 Privacy, confidentiality and records.
Social Workers will:

(a) Divulge confidential information only with the consent of the service user or informant, except where there is clear evidence of serious risk to the service user, worker, other persons or the community, or in other circumstances judged exceptional on the basis of professional consideration and consultation, limiting any such breach of confidence to the needs of the situation at the time



Common Core

"Understand how to present genuine choices to young people and how to obtain consent to sharing information."


Contrast the professional Code of Ethics with the Common Core of Skills and Knowledge for the Children's Workforce.

What is astounding about this extract is the ironic linking of two skills. If obtaining consent is to be consequent upon a genuine choice, what other choice is offered? If the core skill is the outcome of consent, is that not inconsistent with genuine choice?

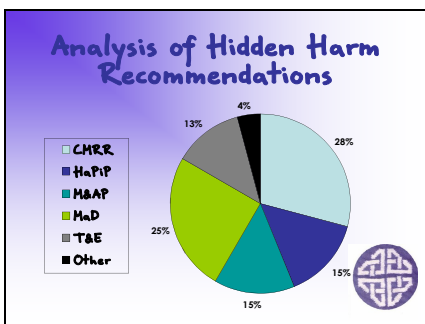
Experience from recent practice is that, consistent with the government's cavalier approach to privacy in relation to databases, informed consent is frequently overlooked; indeed, a number of arguments are put forward that there is no need for informed consent.

Information Commissioner

"Consent should always be freely given, thus any document prepared by the data controller to obtain consent should not contain any coercive element, and lack of consent should not generally cause any detriment to the individual, particularly in respect of any statutory rights that individual has.
(Information Commissioner, 2006).



Contrast the view of the Information Commissioner on the nature of consent to information sharing and how it impacts on services.



CMRR – Count, Measure, Record, Research
HaPiP – Have a Policy in Place
M&AP – Motherhood and Apple Pie
MaD – Make a Difference
T&E – Train and Educate

'Motherhood & Apple Pie'

6. "The voices of the children of problem drug users should be heard and listened to."



Motherhood and Apple Pie – a phrase denoting things that are likely to be universally accepted as good things...

Another example is recommendation 40:

"40. Given the size and seriousness of the problem, all non-statutory organisations dedicated to helping children or problem drug or alcohol users should carefully consider whether they could help meet the needs of the children of problem drug or alcohol users"

'Other'

7. "Work is required to develop means of enabling the children of problem drug users safely to express their thoughts and feelings about their circumstances."



The irony here is that, based on the research looked at earlier, one of the things that will enable "the children of problem drug users safely to express their thoughts and feelings" is a move away from the obsession with counting, measuring and recording, and in particular sharing information, as this will enhance trust in the adults and the agencies they work for.

Summary

- ✓ Ethical issues
- ✓ Legal issues
- ✓ A better way?




Ethical issues

- ✓ Efficacy of intervention
- ✓ Accuracy of prediction
- ✓ Damaging consequences



Legal issues

- ✓ Infringement of privacy
- ✓ Consent to sharing
- ✓ Accuracy of data
- ✓ Excess of data
- ✓ Secondary purposes



A better way?

- ✓ Resources – to frontline
- ✓ Data – quality not quantity
- ✓ Education – to interpret significance
- ✓ Preventive services – universal
- ✓ Protection – from significant harm
- ✓ Consent – as basis for welfare



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