

THE DANGERS OF INFORMATION SHARING

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Abstract

Both the New Zealand and British governments want to improve children's welfare and are seeking ways of improving preventative and early intervention services. This article critiques the policy being implemented in England with a particular focus on the role given to professionals collecting and sharing information about families as a means of screening children and deciding which ones to target. It is argued that this policy undermines parents and overestimates professionals' ability to predict future outcomes.

INTRODUCTION

Good information sharing is the key to successful collaborative working and early intervention to help children and young people at risk of poor outcomes. (DfES 2006:1)

The belief that more data or information automatically leads to better decisions is probably one of the most unfortunate mistakes of the information society. (Woods and Hollnagel 2006)

These two conflicting views on the value of sharing information, the first by the UK department responsible for children's services in England² and the second by two eminent researchers in cognitive systems engineering, illustrate an important and highly topical debate. Governments in both the United Kingdom and New Zealand have the excellent ambition of improving the welfare and safety of their children and both are considering how to provide more timely and effective services to families. This article reviews the UK government's policy "Every Child Matters" (HM Treasury 2003) and, in particular, the central role it ascribes to increased information gathering and sharing by professionals as the way to decide which families need additional help (for full details of all the proposed and actual databases, see FIPR 2006). Developments in information and communication technology (ICT) have transformed our ability to record, analyse and transmit data. It is now technically possible to collect comprehensive

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- 2 The UK government is responsible for deciding on children's policy for England only; Scotland, Wales and Northern Ireland have separate systems and none are, at present, planning to implement similar information and communication technology solutions.

data on all children within a country and for that data to be dispersed around the various departments and agencies that have some role in children's lives. However, although it is possible, we need to ask whether it is the right thing to do, "right" in both its practical and ethical meanings.

The proposals on the use of ICT are not just small, innocuous, administrative changes in services but are a central part of a new approach to working with families. The UK policy of "Every Child Matters" entails a transformation of the relationship between the State and families. The policy sets out the government's targets and performance indicators for children's development; it ascribes responsibility for achieving the targets not to parents but to professionals working in children's services; and it sets out a scheme for monitoring, screening, and intervening in the lives of children in order to improve attainment of the targets. While the underlying motivation contains a strong and genuine concern for children's welfare, this is tempered by a definition of welfare that is linked to the needs of the State and a failure to acknowledge that the concept itself is contested; children and parents do not always agree with politicians or professionals on what is best for a particular child at a particular point in their lives, nor is there universal consensus on what a "good" adult looks like. Even within professional groups, there is a lack of consensus: social workers in a Scottish study failed to agree on the significance of a child's attachment to a carer or whether harm arose from physical neglect alone (Daniel 1999).

This article takes the subdued view of the value of data sharing captured in the second quote. While there is evidence that professional sharing of information is necessary to uncover concealed cases of abuse and neglect, there is no empirical evidence to support the claim that extensive cross-sectoral data sharing is required to identify other problems experienced by children and parents (Brown and White 2006:3). It will be argued that the proposed network of professional data sharing in the UK is not a significant part of the solution for improving children's welfare and, indeed, may have unanticipated adverse effects. An alternative approach in situations not involving child safety issues is to continue to place parents at the heart of decision-making about children's needs and to focus more on listening to parents and children than on monitoring and making professional judgements about them. The article will draw on the debates and the experiences in England, where the policy is being implemented to bring out the arguments for and against the role of data sharing.

WHAT PROBLEMS ARE WE TRYING TO SOLVE?

Before judging the merits of a proposal or policy we need to be clear about what problems it is intended to help to solve. In both countries, the ambitions for children's welfare are high. In the UK, the government wants "to ensure every child has the chance to fulfil their potential" (The Treasury 2003:6).

Societies' concern for children's welfare has often had a dual motivation of altruism and self-interest (Parton 2006). In the UK, altruism is certainly a motivating force but the urgency of the issue is strengthened by the economic needs arising from the increasingly competitive global market and demographic changes:

We all stand to share the benefits of an economy and society with less educational failure, higher skills, less crime, and better health. (The Treasury 2003:5)

The link between children's outcomes and economic factors is also recognised by New Zealand's Children's Commissioner:

An ageing population structure, with increasing economic dependency and caregiver ratios, means that the future productivity of every child and young person is important. (Children's Commissioner 2006)

Within the overall aim of all children fulfilling their potential, the UK government has identified priority aims:

To reduce the numbers of children who experience educational failure, engage in offending or anti-social behaviour, suffer from ill health, or become teenage parents. (The Treasury 2003:5)

Although the policy change was introduced to the public as a response to the report into the tragic death of Victoria Climbié, a child abused, neglected, and then killed by her great-aunt and partner (Laming 2003), it has a longer genealogy, stemming from New Labour deliberations in the 1990s about improving education and reducing delinquency (Parton 2006). Its origins within the criminal justice system are apparent in its emphasis on *policing* children's behaviour and developmental progress; the original version of the electronic system was called "Identification, Referral and Tracking" (IRT) which has strong associations with criminal investigations.

Before looking at the contribution that more intensive data collecting and sharing could have in achieving these aims, it is helpful to analyse further the key elements in implementing the policy. Firstly, we need to be able to identify who needs help. Secondly, professionals need the knowledge and skills to offer help that puts the children on a more beneficial developmental path. Thirdly, they need the resources to provide that help. All three elements present difficulties but what contribution, if any, can data sharing make?

WHO NEEDS HELP?

A key aim in the new English policy is to increase preventative and early intervention services. This has compelling arguments in its favour: it could reduce the amount of distress and harm experienced by children; it is likely to be easier to solve problems when they are at an early stage; it might lead to more effective solutions that reduce the number of children who enter adulthood with significant problems that are costly to society, i.e. of becoming what Feinstein and Sabates (2006:1) have termed “high-cost, high-harm adults”.

Preventative services can operate at different points in the aetiology (causation) of a social problem. Primary prevention seeks to ameliorate the conditions that create the problem in the first place. Secondary prevention aims to respond quickly when low level problems arise and prevent them getting worse. Tertiary prevention involves responding when the problem has become serious.

With social and psychological problems, as with health, the ideal is to have a successful primary prevention policy that eliminates the problem. The United Nations Convention on the Rights of the Child (UNCROC) provides an internationally agreed set of basic needs of children. Both New Zealand and the UK have seen impressive improvements in meeting the basic social needs of the population in the past 50 years. The universal services of health, education, housing and income support are designed to support and complement parenting, maximising the number of children who develop satisfactorily. In addition to fully universal services, some services in England are specific to areas of extreme deprivation but are then universally available within that area, e.g. the early Sure Start schemes.

However, for some families, universal services are not enough. It is here that the shift in emphasis in the new UK policy is apparent. Historically, in both the UK and New Zealand, children’s services have become significantly skewed towards tertiary prevention, specifically in relation to serious cases of child abuse and neglect (Department of Health 1995, Mansell 2006). Lower levels of abuse and other problems have received less professional attention, despite a continuing policy commitment to secondary prevention. This shortfall in services has been felt in particular by families whose children have physical disabilities or learning difficulties who consequently have suffered considerable stress and family breakdown (Every Disabled Child Matters 2006). It has also been experienced by those families where there are low-level concerns about abuse and neglect. This, too, has been a long-standing source of frustration to those working in the child protection services. Workers meet families whose problems are now severe and hard to tackle but who had clearly shown low level signs of difficulty in the past when the problems would have been significantly easier to

remedy. However, due to the high threshold for receiving a service implicit in a tertiary prevention service, they were not able to access help at that stage, even though many would have welcomed it.

In contrast, the goals of prevention in the new English policy are twofold: firstly, to use risk factor research to identify children who are at higher than average risk of having an adverse outcome; secondly, to collate evidence of low level problems and offer swift intervention to prevent escalation. To achieve these goals, the emphasis is on professionals collectively making judgments about children's needs with the voices of parents and children themselves playing a much lesser role. That is why the collection and sharing of data between professionals is given such a central role in the identification of members of the target groups.

THE RESEARCH BASE

How much can research help professionals to identify which children are vulnerable to poor outcomes?

There is a well-established set of factors that are known to contribute to creating an environment in which children tend to fare badly. The UK policy document summarises these factors (HM Treasury 2003:17):

- low income and parental unemployment
- homelessness
- poor parenting
- poor schooling
- postnatal depression amongst mothers
- low birth weight
- parental substance misuse
- individual characteristics such as intelligence
- community factors, such as living in a disadvantaged neighbourhood.

It is noticeable that, to a great extent, these endorse the set of needs enshrined in UNCROC that are formulated as "rights" that a society should secure for all children, not just those selected by the State. However, what is also noticeable about these factors is that we do not need to collect extensive personal data about children in order to identify where they exist. Data on the existence of many of the factors is already available, such as disadvantaged neighbourhoods, unemployment and low income. Even where more personal data is required, it is mainly in relation to the parents not the child, e.g. postnatal depression and substance misuse.

Besides the more general research on adverse factors in childhood, there are sets of research examining the aetiology of specific social problems, the ones that will be discussed here are the risk factors for child abuse and neglect, delinquency, and social exclusion.

Child abuse and neglect are areas where there have been persistent research efforts to identify which parents are at high risk of becoming abusive. However, screening instruments have, to date, had an unacceptably high level of inaccuracies (Peters and Barlow 2003, Lyons et al. 1996). A federal US review of the available evidence concluded:

That there was insufficient evidence to recommend for or against the use of specific screening instruments to detect family violence for children. (U.S. Preventive Services Task Force 2004:2)

In contrast, in relation to predicting delinquency and anti-social behaviour, the UK government has made strong claims that:

There is now a wealth of empirical data to analyse. The purport of it is clear. You can detect and predict the children and families likely to go wrong. (Blair 2006b)

On the strength of this claim about the research, the government is proposing that midwives carry out a risk assessment and identify which newly born, or unborn children, are likely to grow up to be “a future menace to society” (Blair 2006a). The two main sets of research that the government website references in relation to this policy are on crime and anti-social behaviour (summarized for them by Farrington 2006), and on the prediction of which children will become high-cost/high-harm individuals in adult life (summarized for them by Feinstein and Sabates 2006). Neither of these sets of research provide the evidence to support the political claims that antenatal and post-birth screening and prediction is feasible unless we are willing to tolerate a high level of mis-labelling with all the harm that the label “future menace” (Blair 2006a) will cause to innocent babies.

In relation to criminality, the possibility of accurate prediction is consistently dismissed by academics:

Any notion that better screening can enable policy makers to identify young children destined to join the 5 per cent of offenders responsible for 50–60 per cent of crime is fanciful. Even if there were no ethical objections to putting “potential delinquent” labels round the necks of young children, there would continue to be statistical barriers. 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. (Sutton et al. 2005)

In relation to “high-cost/high-harm” outcomes, Feinstein and Sabates (2006) come to a slightly more optimistic judgment but it has to be remembered that they are considering a wide range of adverse adult outcomes where the base rate is far higher than for serious criminality, e.g. obesity, smoking, and being depressed. Their judgment is also tempered by the warning that children’s risk levels change over time:

Children move in and out of risk in terms of their own development and their levels of contextual risk. Therefore, it is important that the policy mechanisms allocating interventions and support to children and families are flexible and able to track and monitor levels of risk, not always intervening at the first sign of risk but equally able to provide early interventions that may reduce the need for more substantive and costly later interventions. This requires a considerable degree of local practitioner skill. (2006:35)

Politicians are not unusual in being overconfident about the ability of professionals to predict adverse outcomes. People are notoriously bad at intuitive estimates of probability (Gigerenzer 2002). The problem is that they are beguiled by the observation that, when you look into the history of adults with problematic behaviour you often see a record of adverse experiences and problems that now look like early signs of trouble. Where intuition falters, however, is in thinking about how many children had those similar adverse experiences and did *not* become problematic in their behaviour. Without including the base rate of the factor, it is impossible to calculate its predictive value; it is the *relative* incidence of the factor in the subgroup with the problem as compared to the general population and that determines the predictive strength of that factor (Gigerenzer 2002, Munro 2004). Hence, poverty is predictive of serious criminality but it is still true that the large majority of poor people do not become serious criminals.

Having discussed the obstacles to accurate primary prediction, let us now consider issues related to prediction at the secondary prevention level: of identifying low level problems and deciding which ones should have professional intervention. The key problem here is illustrated by politicians’ frequent use of the phrase “early signs”. The issue is that most low level problems get resolved, with or without professional help, and it is only with hindsight that we can look back and say “that low level problem was an early sign of the current serious problem”.

The development of secondary preventative services has always been bedevilled by the level of need. While tertiary services respond to the relatively small group who become seriously problematic, secondary services also need to offer help to the much larger group who have low level problems. Many of these will not escalate but we are unable to identify accurately which ones will. This leads to a resource problem that is discussed in a later section.

DO WE HAVE THE KNOWLEDGE TO SOLVE THE PROBLEMS IN CHILD DEVELOPMENT?

Primary Prevention

In terms of tackling the factors that have been identified as contributing towards creating an adverse environment for raising children, government policies can play at least as big a role as the efforts of individual families. Many of the factors lie outside of the capacity of parents to influence them: they cannot readily alter the quality of the local school or neighbourhood or the level of benefit for the unemployed; homelessness may be a problem they are anxious to solve but are restricted by availability.

Many of the factors are associated with social inequalities and, in the UK and New Zealand, social inequalities have been increasing despite the respective governments' explicit policy aims of reducing them. The UK target of halving child poverty by 2010 is likely to be missed. After initial progress lifted 600,000 out of poverty, the number has started to rise again by 200,000 so that 3.8 million children (about one in three) is living in relative poverty (below 60% of the median income) (Department of Work and Pensions 2007). In New Zealand, the proportion of children living in families with low living standards increased from 36% to 38% between 2000 and 2004 (MSD 2006:65). A UNICEF review of child wellbeing in rich countries placed the UK at the bottom of the league overall (UNICEF 2007). There was insufficient data for New Zealand to be placed but it scored 7th highest out of the 24 rich countries when it came to the percentage of children (16%) living in relative income poverty (p.6).

An interesting example of the impact of economic factors on social problems is provided by a review by the Prime Minister's Strategy Unit on why the UK has seen a steady drop in the crime rate since the mid 1990s. It concluded that 80% of the fall was attributable to economic factors – this conclusion was deleted from the version placed on their website but the original is discussed in Solomon et al. (2007:14).

Secondary and Tertiary Prevention

The new UK policy is, in the main, directed at secondary and tertiary prevention – at responding when children show signs of harm arising from their adverse environmental conditions. It is in this context that collecting and sharing data is considered to play a major role in facilitating the identification of problematic children. Currently, identification of need is mainly done by children and parents themselves, or by professionals in contact with them, rather than by an external screening process.

Given the myriad of physical, cognitive, emotional and behavioural problems that children may have there can be no definitive judgment on the effectiveness of

interventions. However, evidence on effectiveness allows us at most to make modest claims about the ability of professionals to solve different childhood problems (McDonald 2001). This does not imply the gloomy conclusion that most problems are insoluble: many are sorted out with or without professional interventions as demonstrated by random controlled trials. However, for those kinds of problems where there is demonstrated effectiveness, success is nothing like 100%. A New Zealand academic reviewing the effectiveness of a range of interventions designed to reduce delinquency concluded that the success rate ranged between 5% and 50% (McLaren 2000:9). Even though the success rates may be modest, in terms of human wellbeing they are significant and to be valued.

ARE THE REQUIRED RESOURCES AVAILABLE?

For primary prevention, providing the resources needed involves the funding of universal services to a level that ensures all children receive adequate basic care. The political will in both countries to provide such funding is mixed. The basic values of left-wing governments predispose them to wanting to offer all children a decent chance in life but these values are undermined by pressures originating in neo-liberal economics that try to drive down public spending in order to maximise the freedom of the market and so stimulate the economy. Consequently, politicians are in an uncomfortable position. Both the New Zealand and the UK governments can be seen to have done much to reverse the impacts of spending cuts in the 1980s and 1990s but the scale of the problem is immense. For example, it has been estimated that to meet the UK target of halving child poverty by 2010, the government needs to spend an extra £3.8 billion (Barnardo's 2007). This is a dauntingly large amount though, as the children's charity Barnardo's points out, it can be contrasted with the £9 billion that is being spent on hosting the Olympics. Political decisions on spending reflect choices about priorities and it is questionable whether there is sufficient political will to provide the help that families might benefit from.

In terms of secondary and tertiary services, the main, current problem for families and professionals is that there are insufficient secondary level services (Social Services Inspectorate 2003, Every Disabled Child Matters 2006). From their point of view the key problem is not failure to identify the need but lack of access to help because the thresholds for service are so high. It is arguable that while there is such a high level of known unmet need, children's services would be unwise to put their energies into uncovering yet more need that they cannot meet.

The English policy of increasing monitoring and inter-agency data sharing about lower level problems will lead to a huge rise in the number of problems being identified by professionals but there is, at present, no sign that services will have sufficient resources to respond to all, and decisions will need to be made about who should be offered

services. Moreover, screening at this stage has the same problems of inaccuracy as in primary prevention, leading both to injustice for some children of being falsely given an adverse label and to injustice for other families in need who are inaccurately deemed too low risk to merit a service.

To meet the level of known need, the two key resources are trained professionals and money. For both, there are significant issues of availability. In the UK, there are continuing problems of recruiting and retaining staff in social services and nursing. The numbers of health visitors who play a key role particularly in relation to children under five is dropping. In social work, there have been significant problems in recruitment and retention since the mid 1990s, with vacancy rates up to 40% being reported in some areas (Douglas 2002).

CAN SURVEILLANCE BE HARMFUL?

The intentions behind the extended surveillance of children's development are benign but this does not necessarily mean that the effects are benign. A number of concerns have been raised about the dangers of surveillance for family life.

First, there are concerns that it undermines the responsibility and power of parents whose primary role in raising children is enshrined in law (UK Children Act 1989). While it is accepted that the State needs to intervene, often coercively, when there are concerns about child abuse and neglect, the new UK policy will extend the degree of intrusion considerably. The child protection system operates on a negative basis, criticising parents for actions or omissions that are considered harmful but tolerating a diverse range of parenting styles outside of this area. The new system will seek to monitor and judge a much wider range of aspects of parenting in the course of judging children's development and assessing their needs. However, the basis for making such judgments needs to be examined.

There is no one scientifically evidenced style of "good" parenting. While there is sufficient medical evidence to warrant judging whether a child's physical growth rate is within healthy limits, there is no equivalent knowledge base for measuring the connection between parenting styles and cognitive, emotional, and behavioural development. For many aspects of child development, there are rival theoretical approaches, e.g. the psychoanalytic and behavioural schools of psychology. Professionals trained in one approach will reach different assessments about a child than those trained in the other.

In the UK policy, children who are considered to have needs in addition to those met by the universal services will have a "Common Assessment Framework" form completed on them and their families. This form requires a judgment about whether disciplinary

methods used by the parents are “appropriate” and this provides a good example of the difficulty. Consensus can probably be reached about some practices that are definitely “inappropriate” but there is considerable disagreement about what is acceptable. The recent debates in New Zealand about whether smacking was appropriate or not illustrate the high degree of controversy that such judgements can arouse. There is a danger that parents will find themselves at the mercy of whoever is carrying out the assessment of their child, with some professionals considering their behaviour acceptable and others criticising it.

Scientific knowledge is not all that matters when it comes to assessing children. Assessment unavoidably involves values and beliefs about how a person ought to behave. Societies have always recognised that moral values and religious beliefs play a significant part in determining how parents bring up their children and contemporary societies seek to tolerate the cultural diversity that exists.

A second issue of concern is the inaccuracy of risk predictions. Any risk prediction leads to a number of false positives and false negatives. This raises the question of what number of false positives (children inaccurately deemed at risk) is acceptable. This is a moral not a scientific judgement (Hammond 1996). The risk predictions stemming from the application of the new policy will have serious stigmatising consequences for children who are considered “at risk” of some adverse outcome. The Prime Minister, for example, has talked of midwives identifying “the future menaces to society” in utero (Blair 2006a). A child born with this label will find the world treats him or her differently as a result. How many innocent babies is it acceptable to harm by mislabelling them? Indeed, how harmful might the label be even if proved correct?

A third area of concern about surveillance is its impact on the relationship between family members and professionals. Confidentiality has been a major principle in the caring professions except in cases of child abuse and neglect. However, data sharing is a key element in the proposed electronic system and the UK government has pledged to “remove the legislative barriers to better information sharing” (HM Treasury 2003:13). Evidence suggests that the loss of a guarantee of confidentiality will affect parents’ and children’s willingness to confide in professionals (Munro 2007). Research on children’s views has consistently found that they accept the need for information sharing when there are concerns about significant harm but, on other matters, they are reluctant to talk if there is a risk that the information will be divulged to others (Children’s Rights Alliance for England 2006, Hilton and Mills 2006). Indeed, even with child abuse, the lack of confidentiality has a negative effect. Research on children using ChildLine, a confidential phone service, highlighted the importance of the confidentiality:

The offer of confidentiality is one of the prime reasons children call ChildLine. One of the most common questions they ask of our counsellors is, “Are you going to tell anyone about this?” (Easton and Carpentieri 2004:25)

The fourth and final concern I wish to consider is the risk that children who are being abused and neglected may be afforded less protection by the State under the new system. This echoes the concern in the quote at the beginning of this article that it is a mistake to assume that more information leads to better decisions. At first glance, increased surveillance might be thought to lead to a greater chance of seeing which children are suffering but, in reality, there are serious grounds for concern. The basic problem is that by magnifying the amount of data being collected so much, there is a risk that cases of serious abuse will be hidden in the deluge of data about lower level concerns. The reality of this risk is well-evidenced by experiences in other areas of data collection (Anderson 2001). The UK Information Commissioner, giving evidence to the Select Committee for Education and Skills, summed up the problem: “when you are looking for a needle in a haystack I am not sure it is wise to make the haystack even bigger” (Information Commissioner 2005).

CONCLUSION

Economic and political changes are altering the environment in which children are raised. The competitive impact of the globalisation of the economy makes it more important for both New Zealand and the UK to have a well educated workforce capable of carving out a place in the global market. At the same time as external economic forces are increasing governments’ concern about children’s development, neo-liberal economic policies are seeking to reduce public spending on universal services that, in the days of the welfare state, made a major contribution to providing the benign environment in which children could flourish. In the UK, social inequalities have widened considerably since such economic policies were first introduced by the Conservative government in 1979. The social and individual factors that are predictive of poor outcomes for children have worsened with child poverty, for example, going from one in ten to one in three children. As a result, the primary preventative strategies have been less successful.

Both countries experienced a period of more extreme neo-liberal economic policy at the end of the 20th century and now have governments that are trying to reverse the effects this had on children. The New Labour government in the UK has been making efforts to tackle many of the factors, such as poverty, poor schooling and poor neighbourhoods, that influence children’s development. At the same time as working on primary preventative strategies, it has also been trying to improve secondary prevention – providing help for lower-level problems so that some at least are prevented from escalating into serious, tertiary-level problems.

It is in this area that the government has seen a role for surveillance, screening, and targeting of children and parents. By creating a professional network monitoring

all children's development and by making it responsible for ensuring that children achieve the targets that the government has set for their development, the government is radically reducing the responsibilities of parents and redefining the relationship between the State and the citizen.

The key factors associated with this policy seem threefold. First, there is a concern to keep costs down by limiting services to those children assessed as at high risk of the key adverse outcomes of poor school achievement, delinquency, ill health and early parenthood. Secondly, there is an unjustified level of confidence in the ability of professionals to make accurate screening judgements and to offer effective help. Thirdly, there seems to be a loss of confidence in parents, a belief that they can no longer be trusted to have their children's welfare at heart, or perhaps a concern that they will not share the same priorities as the government.

This article has not opposed the aim of offering more primary and secondary preventative help to families; it has taken issue with the way this is being done. It entails a shift in the balance of power between families and professionals, and this has been criticised on both pragmatic and ethical grounds. There is a lack of evidence that professional monitoring and screening, using an agenda set by the government, will do better in improving outcomes for children than a good professional network that listens and responds to the worries of children and parents.

It is an irony of neo-liberalism that as the State increasingly withdraws from the economic market, it becomes increasingly involved in the surveillance and regulation of individuals.

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