KEYNOTE PRESENTATION

Can Joined-Up Data Lead to Joined-Up Thinking? The Western Australian Developmental Pathways Project

La mise en commun des données mène-t-elle à la mise en commun des idées? Le projet Western Australian Developmental Pathways

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Abstract

Modern societies are challenged by "wicked problems" – by definition, those that are difficult to define, multi-causal and hard to treat. Problems such as low birth weight, obesity, mental ill health, teenage pregnancy, educational difficulties and juvenile crime fit this category. Given the complex nature of these problems, they require the best data in order to measure them, guide policy frameworks and evaluate whether the steps taken to address them are actually making a difference. What such problems really require are joined-up approaches to enable effective solutions. In this paper, we describe a unique initiative to encourage a more preventive, whole-of-government approach to these problems – the Developmental Pathways Project, which has enabled the linkage of a large number of de-identified administrative databases in order to explore the pathways into and out of the negative outcomes affecting our children and youth. This project has not only enabled the linkage of agency data, but also of agency personnel, in order to improve and promote cross-agency research, policy and preventive solutions. Through the use of these linkages we are attempting to shift the paradigm to encourage agencies to appreciate that these "wicked problems" demand a preventive approach, as well as the provision of effective services for those already affected.

Résumé

Les sociétés modernes font face à d'« épineux problèmes », soit ceux qui sont difficiles à définir, qui résultent de multiples causes et dont le traitement est complexe. Des problèmes tels que l'insuffisance de poids à la naissance, l'obésité, la maladie mentale, la grossesse chez les adolescentes, les difficultés d'apprentissage et la criminalité juvénile font partie de cette catégorie. Étant donné leur nature complexe, il est nécessaire d'obtenir les meilleures données pour les mesurer, orienter les politiques et évaluer l'impact réel des mesures prises pour y remédier. En réalité, ce qu'il faut pour traiter ces problèmes est l'adoption de démarches communes pour mettre au point des solutions efficaces. Dans cet article, nous décrivons une initiative originale qui vise à favoriser une démarche plus préventive et pangouvernementale, soit le projet Developmental Pathways qui a permis de mettre en lien un grand nombre de données administratives anonymes afin d'examiner le parcours en matière de résultats négatifs chez les enfants et les jeunes. Ce projet a permis de mettre en lien non seulement les données des organismes, mais aussi celles de leur personnel, de sorte à promouvoir et améliorer la recherche, les politiques et les solutions préventives au niveau transorganisationnel. Ces liens visent à modifier le paradigme, et ce, en vue d'inciter les organismes à comprendre que ces « problèmes épineux » nécessitent l'adoption d'une démarche préventive de même que la prestation de services efficaces pour ceux qui en souffrent.

* * *

Modern societies are challenged by "wicked problems" (see Box 1) that demand the best data in order to measure them, guide policy frameworks and evaluate whether the steps taken to address them are actually making a difference. A list of "wicked problems" challenging Australia (and many other developed countries) appears in Box 2.

BOX 1. Wicked problems

- Are socially complex with multiple layers of stakeholders
- Are difficult to define clearly, and there is often disagreement about the cause
- Are interdependent and often multi-causal
- Have no clear or "correct" solution
- Defy conventional approaches to problem-solving
- Are cross-cutting, i.e., do not fit into organizational silos

The list includes a range of child and youth problems (Stanley et al. 2005) that are the focus of population research at the Telethon Institute for Child Health Research in Western Australia (www.ichr.uwa.edu.au) and in a national alliance we have established to encourage effective policies and implementation (Australian Research Alliance for Children and Youth; www.aracy.org.au). By "wicked" we mean that these problems are complex in causation, have few effective treatments, and cross multiple agencies and professional groups in terms of the responses needed to address them. Their impacts are also extremely costly (Collins and Lapsley 2008).

Primary prevention of many of these problems will result only when attention is paid to the very fabric of our societies, such as how our economies are managed for social equality and participation across the whole population, and whether there is a culture of valuing children, young people and those who care for them. The variability in measures of child well-being (e.g., health, safety, income, education) observed across wealthy OECD nations (UNICEF 2007) raises questions as to whether such problems can be explained by policy differences across these nations. If we can identify the relative importance of policies, then we can attempt to change them in those countries where there is obvious room for improvement (such as Canada and Australia). A vital policy question for both Canada and Australia is why we continue to fail in effectively delivering most services in health, mental health, education, child protection and justice to our most vulnerable, including Aboriginal and socially disadvantaged people.

On the whole, the response of health and welfare agencies to these very challenging issues has been to focus on the ends of pathways when most of these problems are harder to manage or treat and success in avoiding harm or damage is less likely. In spite of these difficulties, agencies attempt to measure their massive investments in these areas by analyzing trends in the problems' occurrence. We need a paradigm shift to get agencies to appreciate that these problems demand a preventive approach *as well as* the provision of effective services for those already affected. Most pathways to juvenile crime commence in early childhood or even in utero, or via intergenerational environments. An example of such a pathway would be that involving foetal alcohol exposure and its consequences.

Solutions, particularly those aimed at successful prevention, are more likely to come from multiple agencies working together (e.g., our definition of "joined-up thinking" and what others may define as cross-agency or whole-of-government strategies). Agencies responsible for intervening earlier are often different and remote from the role and expertise of the agency responsible for the end-stage outcomes. An example from our own work is health workers' reducing the risk of potential child abuse and neglect through identifying children born with neonatal withdrawal syndrome and providing support and referral to substance-using mothers (O'Donnell et al. 2009).

Hence, in this paper we want to address the question of whether joined-up data (i.e., de-identified data that have been linked at the individual level) can lead to joined-up thinking by describing the experience of a novel capacity developed in Western Australia (WA). The Developmental Pathways Project is a unique collaboration between our institute and 11 government agencies. We are using de-identified individual records, linked across several government agencies that collect data for a range of administrative purposes. This collaboration brings together researchers, policy makers and community members to quantify the extent to which the main pathways into child and youth problems traverse these agencies, demonstrating their joined-up nature and answering policy-relevant questions.

BOX 2. Wicked problems challenging Australia

Poor Health and Well-being
- Low birth weight
- Complex diseases (asthma, diabetes, obesity)
- Mental ill health
- Substance abuse (foetal alcohol syndrome)
- Teenage pregnancy
- Disabilities

Social Disease
- Child abuse/domestic violence
- Behavioural problems/disengaged youth
- Educational problems
- Juvenile crime
- Workplace stress
- Reduction in human capital

Environment
- Climate change
- Environmental degradation
- Water resources
- New and emerging infections

The WA Population Health Data Linkage System

We have used population health data, including registers, for more than 30 years in WA (Stanley et al. 1994), with linkages done regularly between all births, midwives' notifications, hospitalizations, deaths, mental health services and our total population registers (birth defects, cerebral palsies, intellectual disabilities, autism, cancers).

These data are either statutory collections (e.g., births, deaths, midwives' notifications), agency data (hospital morbidity, child protection) or special population registration of cases of diseases or problems (often research funded, e.g., birth defects). All are collected without consent under national and state-based guidelines pursuant to privacy legislation to enable secondary use of data for monitoring and research in public health and health services (NHMRC 2000).

These linked data sets enable a large number of epidemiological and health services research projects to investigate causes, suggest preventive and other strategies, evaluate medical care and inform policy frameworks (Brook et al. 2005; Hillman et al. 2000; Jablensky et al. 2005; Hansen et al. 2002).

Advantages and Limitations of Population Data Record Linkage

The linking of population data at the individual level offers a number of important advantages compared with other research designs: (a) it is relatively cheap, using existing and available data; (b) it captures the total population, including those at highest risk or with other characteristics that make them least likely to participate in, or to be included in, surveys, cohort studies and randomized controlled trials (resulting in biased participation and loss to follow-up); (c) it includes the total population, an approach that usually ensures adequate statistical power for robust analyses; (d) it includes all birth cohorts, allowing investigation of the effects of changes over time in family, societal and environmental factors (compared with single birth cohort studies); (e) it provides the basis for research and policy evaluation across all groups in the population; and (f) it allows analyses of sensitive information that is hard to collect via survey methods (e.g., mental health, child maltreatment, criminal behaviour, drug use, termination of pregnancy).

Of course, agency data are limited to what is collected by each agency, and many variables relevant to child development (e.g., developmental milestones, parenting style) are not collected. Therefore, in addition to these population data, our institute engages in a range of other epidemiological studies such as population surveys, case control and cohort studies, and randomized controlled trials. All studies are conducted with full consent, and for all studies conducted since the late 1990s, we have sought permission (and received it in well over 95% of cases) to link these data with the population data. So although we have limited but still useful data on all individuals, the additional complementary studies allow us to obtain a more complete picture.

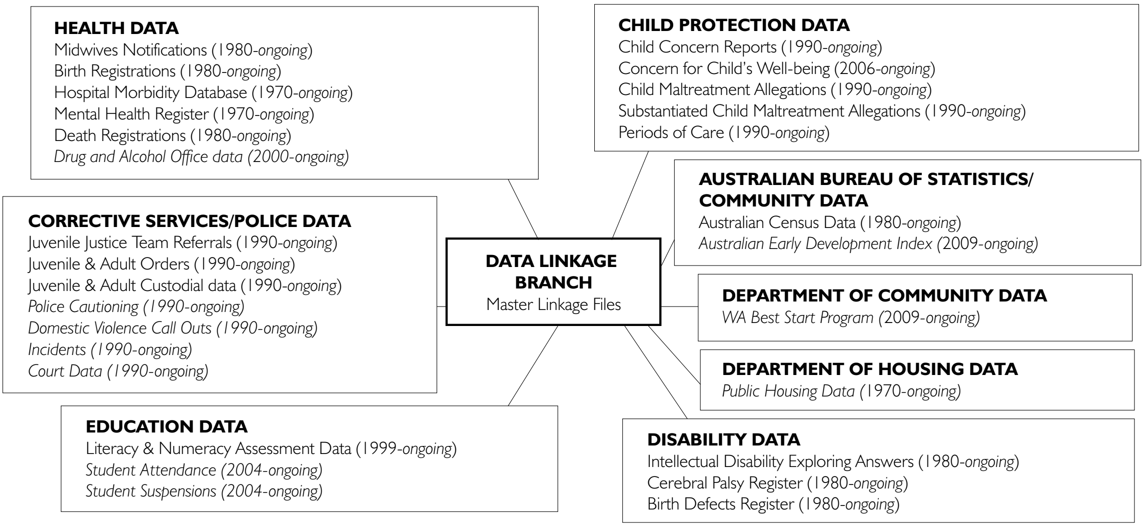
These other studies and their linkages also enable us to imbed them in a total population sample, thereby testing their generalizability and participation bias. They also provide multiple opportunities to validate a range of variables in the population data, such as diagnostic, demographic and ethnic information. The population data linkage expands the capacity of the sample surveys and cohort studies, converting the former into quasi-longitudinal studies and, in the case of the latter, enabling some information on those lost to follow-up. Because the information available in the total population agency data is limited, these linkages to in-depth studies enable better interpretation and analysis of the developmental pathways of interest.

Extending health data linkage to educational and welfare agency data: The Western Australian Developmental Pathways Project

Our institute, in collaboration with government agencies, recently succeeded in winning two research grants to extend further our population health data to enable linkage across agencies for a range of developmental and behavioural problems. The overall aim was to enable more "joined-up," "integrated" or "whole-of-government" thinking in relation to the costly and distressing issues that affect children and youth in WA. The Developmental Pathways Project

(DPP) has been in place for five years. Figure 1 lists agencies involved, the data currently linked and the data planned for linkage (shown in italics).[1] Other collaborators include the departments of Indigenous Affairs, Attorney General and Treasury and Finance.

FIGURE 1. Agencies involved in the Developmental Pathways Project



This unique project has had remarkable success. We have managed to obtain and link data from a large number of agencies, with more becoming involved. We have engaged with the agencies to ensure that the projects serve their policy needs, and we have developed a system of governance that enables excellent interactions among the agencies and data custodians, agency heads, the head of Treasury, the researchers, the data linkage unit and the doctoral students who do much of the work.

A novel aspect is that the doctoral students are co-supervised by both academic and policy experts. This means that in addition to the various committees set up to connect the researchers and the agencies, each project has dedicated policy input guiding them throughout. Hence, not only do the students produce publications for scholarly journals; they also write policy briefs, present to agency staff and conduct additional analyses specifically to serve a policy agenda. Examples of some of the work that has been achieved through the project include our work on prior hospital morbidity of children in contact with the child protection system (O'Donnell et al. 2010); birth outcomes and educational achievement (Malacova et al. 2008); and the impact of baby bonus payments on birth rates (Langridge et al. 2010).

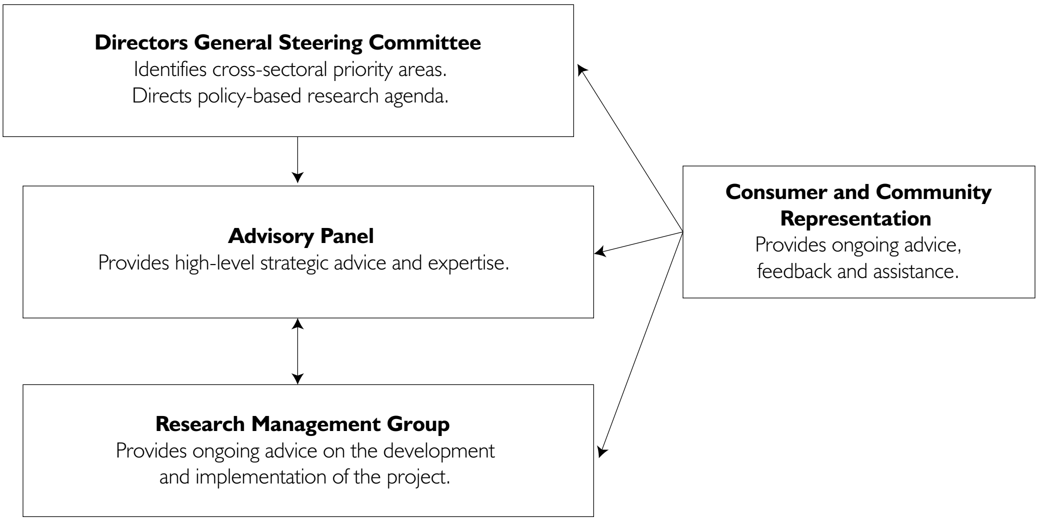
The role of community participation and governance structure

In 2002, the Telethon Institute for Child Health Research, with support from the state's peak consumer organization, the Health Consumers' Council, commenced a long-term strategy to enhance and increase consumer and community participation in its research activities. This strategy has resulted in a strong, sustained consumer and community engagement program that includes the following components:

- a dedicated consumer advocate on staff;
- a well-developed governance and policy framework for participation, including the establishment of a Consumer and Community Advisory Council;
- budgeted participation activities for consumers and community representatives in research grant applications;
- the development of a range of models for consumer and community participation;
- training events relevant to participation for researchers and consumer and community representatives; and
- integrative forums known as "community conversations," which bring researchers, other professions and consumer representatives together.

Participation and engagement from consumers and community members is being sought in this project to ensure that (a) knowledge and experience are shared, to assist in guiding the research process; (b) the research is consistent with community values and aspirations; (c) advice and feedback are incorporated into the research process; (d) the interpretation of results and the drafting of recommendations are accurate, valid and culturally appropriate for translation of the findings into policy development; and (e) research findings are communicated and disseminated to key stakeholder groups and community organizations. Consumer and community representation will be sought at every level of the DPP's governance structure (Figure 2).

FIGURE 2. Project governance structure



Senior DPP staff used a "community conversation" process to include the consumer and the community voice in the development of the 2009 DPP grant application. Researchers, members of the Consumer and Community Advisory Council, and Aboriginal and non-Aboriginal community members met to learn about the current research and to discuss community priorities for future research projects. The feedback from this meeting had a twofold positive outcome, i.e., the inclusion of community suggestions – for example, the inclusion in the grant application of questions about appropriateness of services and service use – and the addition of the WA Department of Housing to the government agencies involved in the project.

Consumer and community representation has been greatly facilitated by the consumer research liaison officer and the manager for the Kulunga Research Network (a partnership with the WA Aboriginal community) at the Institute. Their help has enabled collaboration with the Institute's Consumer and Community Advisory Council and the Aboriginal Collaborative Council Advising Research and Evaluation (ACCARE), community groups and organizations.

The project's governance structure encourages maximum involvement by all members of the project team, ownership, clear lines of communication, transparency and translation of the research, all of which are vital to the success of the project.

Privacy protection

The protocols and procedures employed by the Data Linkage Branch at the WA Department of Health to link data are now accepted as international best practice (Kelman et al. 2002). The protocols were developed to minimize the risk to privacy while maximizing link efficiency. Individual identifying information is restricted to a specialized team who create the linkage keys. Under memoranda of understanding (MOUs) between the Department of Health and each of the agencies providing data, strict processes are outlined, identifying the methods of linkage, extraction and hand-over for data. These MOUs also enable ownership of data to be maintained by each agency.

This process has reduced the use of identified data supplied by the Health Department for research purposes (Trutwein et al. 2006), and has enabled the research of sensitive issues (e.g., mental health problems, child abuse and juvenile delinquency) while protecting the privacy of participants.

To maintain the privacy and confidentiality of the data entrusted to researchers on this project, the researchers are governed by confidentiality policies and the National Privacy Principles.

Has the DPP encouraged joined-up thinking? Has this process informed policy?

We anticipated that the joined-up data would mostly influence policy frameworks rather than specific policies. We aimed to (a) shift thinking towards prevention and early intervention strategies; (b) increase interest in whether the data could guide policy approaches that targeted high-risk groups or were universal across the whole population; (c) identify those subgroups of the population for whom services work best and those for whom they fail; and (d) identify "paradoxical" groups that did well in spite of poorer circumstances and more risk factors.

Although the process is still young, we believe that there is evidence that this project has resulted in joined-up thinking across bureaucracies, not just as a result of the data, but also because of the governance structures set up around the project. A shift has begun from academics deciding on linked projects to the agencies requesting their agendas. The heads of all agencies involved attend two meetings a year to decide on priorities. The list of research questions generated by the directors general of departments (Box 3) demonstrates that they are now thinking across departmental silos with projects that benefit from the cross-agency data linkages, the developmental aspects of pathways, and the high priority placed on prevention in their agendas. The leadership from the head of the Treasury was key to engaging all the heads of the other agencies. They are starting to view this cross-agency data and capacity as a vehicle for whole-of-government, joined-up thinking.

BOX 3. Examples of research questions developed in consultation with the Directors' General Steering Committee and Community Advisory Group

1. What are the early childhood characteristics of those who develop mental illness?
2. What are the characteristics of Aboriginal children and youth not in contact with the justice system?
3. What proportion of people in juvenile detention have pre-existing mental health problems?
4. What are the characteristics and precursors of those who enter the juvenile justice system, and how and when can we attenuate these particular risk factors?
5. What are the characteristic pathways of children with a disability who enter care and protection?
6. What are the health and social problems contributing to poor educational performance?
7. What are the outcomes for children who have a substantiated child maltreatment allegation who enter care?
8. Identify poor geographical areas with good educational outcomes and examine their characteristics.

An example of policy developments and practice changes as a result of our research is our work on neonatal withdrawal syndrome (O'Donnell et al. 2009). Our government briefing paper led to an invitation to present our results and recommendations to the Impact of Parental Drug and Alcohol Use on Pregnancy, Newborns and Infants Working Party, an interagency group responsible for prevention and intervention in this area. Meetings were also held at WA's primary maternity hospital on the needs of these women and long-term follow-up. This collaboration has resulted in the strengthening of the pre-birth interagency protocols among the departments of Child Protection and Health, as well as a review of follow-up and secondary services for these women.

Challenges in this project relate to the capacity and time of bureaucrats to participate, rapid turnover of staff and changes in government departments, the need to collect more qualitative information to inform policy questions, adequate descriptions of policy and practice to enable evaluation, and development of appropriate communications strategies to inform our community about the public good that arises from using data in this way and how we protect privacy.

Summary and Conclusions

Pathways into major adverse outcomes for children and youth start very early, as they did even in the previous generation. This fact poses huge challenges for both prevention and the future planning of crisis services, such as disability, health and education services for the increasing proportions of surviving very preterm infants or of children exposed in utero to alcohol. Many of the early risk and protective factors (e.g., growth in utero; harmful antenatal exposures; social disadvantage; parental, particularly maternal, educational level; maternal pregnancy factors; geographic location) are seen in a range of outcomes, currently handled in silos by separate bureaucracies.

The early promise of this WA data linkage project – which encourages agencies to use their own data in novel ways, bridging jurisdictions to understand these problems – shows promise in generating a more appropriate policy framework, leading to more balanced and humane solutions.

ACKNOWLEDGEMENTS

We would like to acknowledge the support and assistance we have received from all of our Industry partners particularly the Western Australian Department of Health, the Data Linkage Unit and the Western Australian Department of Treasury and Finance. We would also like to acknowledge the Australian Research Council for funding two linkage grants (LP 0455417 and LP 100200507).

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NOTE

[1] ABS data are not unit record data.

REFERENCES

Brook, E., D. Rosman, C. Holman and B. Trutwein. 2005. *Summary of Research Outputs Project. Western Australian Data Linkage Unit (1995–2003).* WA Department of Health, University of Western Australia, Telethon Institute for Child Health Research, Curtin University of Technology, Perth.

Collins, D. and H. Lapsley. 2008. *The Costs of Tobacco, Alcohol and Illicit Drug Use to Australian Society in 2004/05.* National Drug Strategy Monograph Series No. 64. Canberra: Department of Health and Ageing.

Hansen, M., J.J. Kurinczuk, C. Bower and S. Webb. 2002. "The Risk of Major Birth Defects After Intracytoplasmic Sperm Injection and In Vitro Fertilization." *New England Journal of Medicine* 346: 725–30.

Hillman, S., S. Silburn, A. Green and S. Zubrick. 2000. *Youth Suicide in Western Australia Involving Cannabis and Other Drugs. A Literature Review and Research Report 2.* Perth: Western Australian Drug Abuse Strategy Office.

Jablensky, A.V., V. Morgan, S.R. Zubrick, C. Bower and L.A. Yellachich. 2005. "Pregnancy, Delivery and Neonatal Complications in a Population Cohort of Women with Schizophrenia and Major Affective Disorders." *American Journal of Psychiatry* 162(1): 79–91.

Kelman, C.W., A.J. Bass and C.D.J. Holman. 2002. "Research Use of Linked Health Data – A Best Practice Protocol." *Australian and New Zealand Journal of Public Health* 26(3): 251–55.

Langridge, A.T., N. Nassar, J. Li, P. Jacoby and F. Stanley. 2010 (under review). "The Effect of Monetary Incentives on Birth Rates in Australia." *Journal of Community and Epidemiology Health.*

Malacova, E., J. Li, H. Leonard, N. de Klerk and F. Stanley. 2008. "Association of Birth Outcomes and Maternal, School, and Neighbourhood Characteristics with Subsequent Numeracy Achievement." *American Journal of Epidemiology* 168: 21–29.

National Health and Medical Research Council (NHMRC). 2000 (March). *Guidelines Under Section 95 of the Privacy Act 1988.* Retrieved October 26, 2010. <http://www.nhmrc.gov.au/publications/synopses/e26syn.htm>.

O'Donnell, M., N. Nassar, H. Leonard, R. Hagan, R. Mathews, Y. Patterson and F. Stanley. 2009. "Increasing Prevalence of Neonatal Withdrawal Syndrome." *Pediatrics* 123: e614-621.

O'Donnell, M., N. Nassar, H. Leonard, P. Jacoby, R. Mathews, Y. Patterson and F. Stanley. 2010. "Rates and Types of Hospitalisations for Children who Have Subsequent Contact with the Child Protection System: A Population-Based Case-Control Study." *Journal of Epidemiology and Community Health* 64: 784–88.

Stanley, F.J., M.L. Croft, J. Gibbons and A.W. Read. 1994. "A Population Database for Maternal and Child Health Research in Western Australia Using Record Linkage." *Paediatric and Perinatal Epidemiology* 8: 433–47.

Stanley, F., S. Richardson and M. Prior. 2005. "Children of the Lucky Country? How Australian Society Has Turned Its Back on Children and Why Children Matter." Sydney: Pan Macmillan Australia.

Trutwein, B., C.D. Holman and D.L. Rosman. 2006. "Health Data Linkage Conserves Privacy in a Research-Rich Environment." *Annals of Epidemiology* 16: 279–80.

United Nations Children's Fund (UNICEF). 2007. *Child Poverty in Perspective: An Overview of Child Well-being in Rich Countries. Innocenti Report Card 7.* Florence: UNICEF Innocenti Research Centre. Retrieved October 26, 2010. <www.unicef-irc.org/publications/pdf/rc7_eng.pdf>.