

Markle Program and Organizational Highlights 1999 – 2004

Over the last two years, the Markle Foundation has primarily focused its work in two areas where information technology (IT) holds great promise to benefit our society: health and national security. This focus grew out of a broader undertaking, initiated in 1999 as IT and Internet policy were emerging rapidly, to stimulate the participation of many needed actors in the public interest potential of IT.

The following represents an overview of some of Markle's major initiatives, projects and contributions to public benefit over the past four years. Our activities during this time were pursued in three program areas: *Information Technology for Better Health, Policy for a Networked Society* and *Interactive Media for Children*.

Information Technology for Better Health

Markle's health program aims to accelerate consumer use of information technologies in ways that improve the quality of health and health care based upon a consumer centric vision. The widespread diffusion of IT is essential to the realization of this vision because technology alone makes possible the high level of information distribution, access, control, and intelligence on which the vision depends. Among the strategies we have used to achieve this vision:

• Focusing the attention of thought leaders and the public on policy

barriers to the development and use of consumer health/IT applications, and working to facilitate the collaboration of diverse groups in addressing these barriers.

- Building the case for the use of consumer health/IT applications by providing evidence of their positive impact.
- Facilitating the development of consumer health/IT applications with those characteristics that we believe have especially great potential to transform healthcare and consumers' relationship to it.
- Using a combination of new and old media to increase consumers' expectations about the extent to which they can actively participate in their own health care.

The flagship project that addresses most of these objectives is the Connecting for Health Collaborative: a Public-Private Collaborative. Over the past year and a half, Markle has convened an extraordinary group of government, industry and healthcare leaders that has led the national debate on electronic clinical data standards. Early in its inception, the group drove consensus on the adoption of an initial set of standards, developed case studies on privacy and security and helped define the electronic personal health record (PHR).

Most recently, Markle announced the second phase of Connecting for Health: the creation of a Roadmap for achieving electronic connectivity in healthcare. For this phase, the Markle Foundation is pleased that the Robert Wood Johnson Foundation will also be supporting our effort. The collaborative will also be developing solutions for overcoming specific barriers to electronic connectivity and then setting up a demonstration project to test solutions under real-world conditions. (For more information on Connecting for Health please see

www.connectingforhealth.org.)

Other projects that have contributed to our strategy include:

- Life on the Line is a unique initiative combining the powers of TV and the Internet to inspire and enable women to take control of their health and health care. Life on the Line makes first-rate information and tools available to a mass audience and also serves as a model for the effective melding of different types of media to enhance the public's knowledge and attitudes-research indicates that most women exposed to it learn something and change the way they think about health. According to research carried out by the Foundation for Accountability (FACCT), women who saw the Life on the Line TV program and used the web site were significantly influenced by them: more than 80% learned something about health, while more than 60% changed their thinking about health and health care.
- The Markle Telemedicine Clinic in Cambodia was a collaboration between American Assistance for Cambodia, Partners Telemedicine, and the Sihanouk Hospital Center of Hope and the Markle Foundation. The clinic uses the Internet to bring the expertise of some of the most highly trained and respected American doctors to a remote

Cambodian province that suffers from a lack of access to health care services. The clinic provides an innovative model for remote care in the developing world.

- The Patient Accessible Electronic Medical Records project, in partnerships with Partners HealthCare System and Foundation for Accountability (FACCT) is shedding light on the implications of linking patient and doctor via an innovative effort to access medical records online. The research team is also evaluating the potential benefits of patients' providing information about the health care services they receive to be used by the health profession in quality measurement. These inquiries help to establish a much-needed knowledge base to support the Markle Foundation's goal of empowering health consumers, and, ultimately, improving the quality of care.
- The book **Understanding** Healthcare covers a wide array of health topics, including guidance on how to make effective use of the Internet and other high-tech tools to improve personal health. In supporting development of the book, the Markle Foundation furthered its goal of empowering consumers, through information technology-and through information generally-to become more active participants in their own care. Author Richard Saul Wurman, who developed Understanding Healthcare with support from the Markle Foundation, as well as Johnson & Johnson and the

UnitedHealth Group, is a highly acclaimed information architect.

The Comprehensive Health Enhancement Support System (CHESS) was a study funded by the Markle Foundation and the National Cancer Institute (NCI) to evaluate the ways in which underserved women with breast cancer use and benefit from a computerized patient support system. CHESS provides users with up-to-date health information, software to help weigh treatment options, and 24-hour access to medical experts and other patients, all via an Internet connection from home. Findings show a significant positive value of CHESS for underserved patients, indicate that CHESS and participants could be recruited effectively on a large scale using NCI's Cancer Information Services (CIS) phone support network in combination with other outreach vehicles. The program has expanded from a pilot project at the University of Wisconsin to include a significant implementation in rural areas of Wisconsin and inner city neighborhoods of Detroit.

Policy for a Networked Society

The Policy for a Networked Society Program has aimed to enhance the public voice and understanding in technology-related policy making and to achieve policy decisions and outcomes that benefit the public interest. The Policy program has addressed new policy issues resulting from technological and geo-political change as well as traditional policy issues and areas that are being affected by information technology.

The *Policy for a Networked Society* program has pursued four strands of initiatives:

- National Security in the Information Age aims to further the goal of strengthening national security while also preserving civil liberties. This strand has now become one of the top priorities of the Foundation.
- *Policy Participation* has supported transparent, accountable and globally inclusive policymaking processes for Internet and IT policy. Further, it has aimed to expand the pool of thinkers, advocates and non-profit experts to represent the public's interest in key policy discussions;
- Public Engagement through Information Technologies has explored the potential of new media and information technologies to engage and educate a large, diverse population on issues of critical social and individual importance;
- *IT for Development* has aimed to demonstrate how new IT could enable developing nations to accelerate economic growth and social development.

National Security

The cornerstone of our program in national security is The Markle Task Force on National Security in the Information Age. Formed in April 2002, the Task Force focuses on how best to mobilize information and information technology to improve domestic security while protecting established civil liberties. The Task Force, comprised of a diverse and bipartisan group of experienced policymakers, senior executives from the information technology industry. public interest advocates, and experts in privacy, intelligence, and national security, is designed to inform the policy judgments of the federal, state and local governments about the collection and use of information as it relates to national security. It has release two reports, Protecting America's Freedom in the Information Age in 2002 and Creating a Trusted Information Network for Homeland Security in 2003. (For more information on the Task Force please see: www.markletaskforce.org.)

Policy Participation

Our work has focused on creating the expectation in IT policy making that NGO and developing country representatives had to be included with equal dignity alongside government and business, which was path-breaking in a time of industry self-regulation. Markle took the initiative early on with emerging Internet policy issues.

The Markle Foundation has pursued transparent, accountable, multi-sectoral policymaking processes through which government, industry, and non-profits could work together to develop legitimate IT policies that serve the public interest. This work has had a number of significant initiatives and milestones. These include:

 Markle's work to improve public participation in the Internet Corporation for Assigned Names and Numbers (ICANN) through support for ICANN's international on-line election of board members and a set of advocacy and research activities;

- The engagement and leadership of Markle to establish multi-sectoral processes for both the G-8 Digital Opportunity Task Force ("DOT Force"), initiated by the leaders of the Group of Eight (G-8) nations in 2000, and the UN-ICT Task Force, created by the UN Secretary General Kofi Annan in 2002. Both have aimed at developing a global action plan to use IT to support economic and social development.
- The release of the Accountability Framework Report in the summer of 2001, a major survey of U.S. citizens and experts, revealing broad support for multi-sectoral Internet governance and informing U.S. policymakers on public concerns with the Internet;
- The production of the Roadmap for Global Policymaking for IT, which described the challenges developing countries have participating in international IT policymaking venues, and proposed a strategy to address these barriers;
- Markle's support of InterAction, a US NGO umbrella agency, which has sought to expand nongovernmental organizations' use of information technologies to facilitate their humanitarian relief and development work.

In addition, the Foundation also has aimed to build public policy capacity among the public and public interest representatives through several initiatives that targeted young scholars and advocates. We built and fostered Internet-specific policy capacity at established public interest institutions such as the Leadership Conference on Civil Rights, The Carter Center, Common Cause and the Salzburg Seminar in American Studies, and provided major support and resources to the Center for Democracy and Technology to further its leadership in the field. In consultation with the New America Foundation, a non-partisan think-tank, we supported nine year-long Markle Fellowships for individuals who demonstrated the requisite ability and interest to become new thinkers and writers on information technology policy issues. We also initiated the mentoring of young public interest advocates through support of Internet law advocacy clinics at three respected U.S. law schools (The University of California at Berkeley, Stanford University and American University). In recognition of the global significance of the Internet and IT, we have sought to develop global capacity in Internet and technology policy through two programs: a fellowship program for voung and foreign scholars at Oxford University, and the development of a Communications Law Center at the Chinese Academy of Social Science.

In all of these areas, Markle has operated as a catalyst, helping to push the frontiers of Internet policymaking and the design of sustainable and effective solutions.

Public Engagement through Information Technologies

Markle's work in this field has sought to model and encourage the use of communications technology to help people actively pursue knowledge and to participate in a democratic society. The major initiatives undertaken include:

- The Children's Partnership's Contentbank.org, a website premised on the belief that to engage low income people through IT in socially beneficial activities, content that meets their needs must be available. Following rigorous research with regard to Online Content for Low-Income & Underserved Users, The Children's Partnership built a web portal (Contentbank.org), which included critical online resources targeted at staff of community technology programs, after-school programs, libraries, and other places where low-income families can be assisted in the use of digital technologies. Contentbank.org now also provides site-building tools and robust content on jobs, housing, health care, legal and educational services to the growing number of community-based organizations.
- The experiment Web White & Blue 2000, built to coincide with the 2000 national elections, sought to apply the Internet's unique attributes to enable an unprecedented level of individual participation in critical political events and issues. At a time when candidates were not yet focusing on the Internet as a major campaign tool, Web White and Blue 2000 leveraged the power of publicprivate collaboration to provide daily political information, easy access to other useful web sites and special features (such as the Rolling Cyber Debate between the presidential candidates) in order to

enhance the public's experience of the elections. The project was available to more than 85% of the American Internet audience, and brought together 17 of the largest Internet news organizations (such as CNN, the New York Times and the Washington Post), and portals (such as AOL and Yahoo!), as well as thousands of non-profit sites. After 2000 elections, Markle the commissioned a study to examine site usage and its effects on the electorate. The results supported the belief that, while it is too early to tell exactly what impact the Internet will have on democracy, it can change clearly individuals' relationships to the political process.

IT for Development

Markle began its work in IT for Development through its participation in the Digital Opportunity Task Force (the "DOT Force") at the Summit of G-8 leaders in 2000 and over the following two years (see Policy Participation). The Foundation joined with the United Nations Development Programme (UNDP) and the global consultancy firm. Accenture, to review the record and potential of IT to promote development in the poorer parts of the world. Their conclusions were presented to the G-8 leaders at the 2001 Summit in Genoa in a report entitled Digital Opportunity Initiative: Creating a Development Dynamic.

Early in 2002, Markle, UNDP, and other partners joined to assist specific countries in the formulation and implementation of their national IT strategies. For instance:

- Teams actively supported the IT Policy Commission in Mozambique in the finalization of its "Implementation Strategy" for a comprehensive approach to IT for Development, and;
- In the Republic of South Africa, a Markle team participated in the legislatively mandated "e-Strategy Task Team" to reform the nation's communications policy framework.

The Foundation also supported a variety of research initiatives focused on various dimensions emphasized in the Digital Opportunity Initiative. For example:

- Daniel H. Rosen, a Visiting Fellow at the Institute for International Economics, prepared a policy brief on New Directions in U.S. Foreign Assistance and the Role of Information and Communication Technology for Markle in 2002. This report provided the basis for a series of meetings with key U.S. government officials on the value of IT for the U.S. Millennium Challenge initiative.
- The World Resources Institute • successfully undertook a private sector strategy towards IT for development, which sought to catalyze business engagement in IT for development and facilitate entrepreneurial enterprises, and market-oriented solutions. Among the activities supported was a Digital Dividend Clearinghouse, an online surveillance system to track bottom-up, village-level IT for development projects in developing countries; the documentation, in collaboration with leading business schools, of a number of business case studies of innovative and

entrepreneurial examples where IT was used to stimulate productivity, transform markets, and spur development; a "Creating Digital Dividends" conference, in Seattle in November 2000, which brought together major digital companies, entrepreneurs from developing countries, development agencies and foundations, and government officials to explore private sector solutions;

- A Program Related Investment (PRI) in Voxiva enabled the new public health oriented voice and data solutions provider to provide technological solutions for the Ministry of Public Health in Peru. Voxiva continues to do groundbreaking work around the world including several additional projects in Peru and a U.S. Department of Defense contract to help track the spread of diseases in Iraqi and the impact of smallpox vaccinations on U.S. soldiers.
- Bridges.org, an NGO based in a Cape Town, South Africa, has become a leader in the field of ereadiness. To date, it has authored definitive texts on the digital divide and e-policy in Africa, and introduced the concept of "Real Access" to IT – the wide variety of factors that make it possible for low-income people to use technology effectively to improve their lives.
- Professor Ernest Wilson, Director of the Center for International Development and Conflict Management at the University of Maryland, conducted a major study regarding the development of leaders and IT "champions" in a range of developing countries, such

as China, Brazil, South Africa and India.

Markle participated in the creation of the Global Internet Policy Initiative (GIPI) to work in developing and transitional countries to promote the adoption of legal and regulatory frameworks that support the growth of an open, affordable and user-controlled Internet GIPI's local policy coordinators in 17 countries are now convening dialogues and seeking to build informed consensus among all stakeholder groups in their countries. They provide objective expertise on policy issues, commenting on draft legislation, and assist policymakers and civil society in achieving a better understanding of the legal and regulatory environment needed for the Internet to develop.

The need and rationales behind Markle's work in this area have been recognized and carried forward by numerous other organizations, including development agencies, international NGOs and players in the IT industry. We recently published *National Strategies for ICT for Development*, an in-depth study of the lessons Markle learned from our experience in this area, which we hope will be a valuable tool to others working in this field.

Interactive Media for Children

The Interactive Media For Children Program has aimed principally to gain in-depth knowledge about the impact of interactive media on children's learning and development, and has worked to promote the use of that knowledge in the creation of beneficial children's interactive media products.

Interactive Media and Child Development

To create a research agenda addressing the potential for interactive technology to meet children's cognitive, social, emotional and physical needs, Markle developed a project led by Dr. Ellen Wartella, University of Texas at Austin, which produced a report entitled Growing up with Interactive Media: What We Know and What We Don't Know about the Impact of New Media on Children. In addition, a Compendium of current research and directions for the future aimed at increasing access to research on children and interactive media to help academics, producers, parents, and the press to address crucial issues in children's use of interactive technologies, including social development, learning, safety, and consumer awareness.

Building Smarter Products: Unifying Research and Product Development

 Based upon the proposition that interactive media products beneficial to a child's development could also succeed in the marketplace, Markle hosted three Markle Media Forums at which key players gathered to examine interactive media products notable for their incorporation of current child development research into their design. Three in particular were considered: Leap Pad, SimCity and Blues Clues.

To encourage both the non-profit and for-profit sectors to play critical, constructive roles in the development of new interactive TV media for children, the Foundation provided funding to Public **Broadcasting System (PBS) and** The Discovery Channel so that each could create a programming strategy that that was both economically viable and incorporated current research on children and the public interest. PBS's report – "One Voice, Many Screens" – proposed an agenda for the public service media's management of its digital children's television service. In March 2003, The Discovery Channel reported on the implementation of its planning and development processes; the report ultimately reshaped the plan for viewers under ages 5, and marked the beginnings of a new interactive prototype for viewers aged 6-12.

In September 2002, believing that the children's media environment had changed significantly, the Foundation began a period of careful reexamination of program goals and objectives in the Interactive Media for Children program area. The firm Just Kid Inc. provided an extensive environmental scan of the children's interactive learning field. The report concluded that, although there have been a few exceptions; it is in general extremely difficult for innovative research-based children's interactive media projects to gain a foothold in the current media environment. Based on these findings, the Foundation decided to discontinue making investments in the Interactive Media for Children program area.