FROM CAREGIVING TO CARING: A NEW APPROACH TO CIVIC ENGAGEMENT

Lessons from Ruby’s Bequest
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CREDITS

Authors: Rachel Lyle, Jason Tester
Peer Reviewer: Kathi Vian
Production Editor: Lisa Mumbach
Producer & Art Director: Jean Hagan
Design & Production: Robin Bogott, Karin Lubeck, Jody Radzik

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IN MEMORIAM

David Szulborski, 2009
INTRODUCTION

“Help us fix the town that doesn’t care right.”

This intriguing invitation launched Ruby’s Bequest, a project by United Cerebral Palsy and the Institute for the Future to create a collaborative forecast for the next decade of caregiving.

For five weeks during the spring of 2009, participants from many backgrounds and occupations—and with many different forms of engagement in caregiving—shared their stories, frustrations, advice, hopes, and ideas. The platform that supported them was a structured website, managed by a team of facilitators who guided their interactions and created challenges to inspire their best thinking.

Ruby’s Bequest existed in a reality slightly removed from our own, where a small town is forced into a process of civic and very public soul searching when their ability to care for each other is thrown into doubt. As the five weeks of Ruby’s Bequest progressed, this town moved forward even faster, ending in the year 2015, after several years of economic turbulence, technological transformation, and sustained optimism.

Participants from around the world submitted hundreds of stories and ideas, many merging together into collaborative blueprints for a future where solutions for the challenges of caregiving become inextricable from the challenges facing health care systems, civic engagement, and declining cities.

This report presents seven strategies to create the future of caregiving as catalyzed by the stories and ideas from Ruby’s Bequest participants. To distill these ideas even further is to foresee a future of significant disruption to the traditional structures and services of caregiving but also transformative innovation—from baby boomers, their children, technologists, and everyone who is around the world at the end of the 21st century’s first decade, working towards greater engagement with the life of their cities and the lives of their neighbors.
STRATEGY 1: TAP BROADER COMMUNITY ENGAGEMENT TO FILL IN CAREGIVING GAPS

The financial and housing crises of the past year have devastated traditional revenue sources for states and local budgets across the U.S. The cuts necessary to meet revised revenue projections will continue to affect services that benefit the health and social welfare of the communities they serve.

How can we still meet caregiving needs with fewer resources?

Tap into broader community resources to fill the growing gaps in service. Tapping a broader community means reaching people and groups that don’t usually volunteer but want to get involved. Volunteers in local communities have long formed the core of many services in the ecosystem of caregiving, picking up where funding for paid staff ends. But despite a renewed national call to service being championed throughout the Obama administration, volunteering in its traditional form has remained steady for years.

Now, shifts in technology and civic life are converging to fundamentally rewrite the practice—and the potential—of volunteering. In its relatively short history, the internet has evolved from an uncharted and placeless destination of “cyberspace” to become a vital component of the real-world interactions we already value.

Just as significant is the shift from desktop computers to mobile devices that moves our attention from a static and isolated screen toward towards a continuous flow of connectivity in our increasingly mobile lifestyles. This embedding of the internet is driving—and being driven by—a surging spirit of localism. We see a groundswell of re-investment and re-immersion in local community, equipped with access to 21st century tools and new meanings of citizenship that connect these initiatives together.

Networked localism might, however, still be a slow-burning trend if not for the effects of the recent “Great Recession,” sparking widespread interest in new ways to increase levels of volunteering and community engagement. Two recent books—Reset and Life, Inc. by cultural commentators Kurt Andersen and Douglas Rushkoff respectively—document many innovations in local civic society in the U.S. and globally. Both authors reach similar conclusions: while some of this new involvement is certainly catalyzed by economic downturn, the true driver is a pervasive and unmet need for new patterns of living that allow us to create deeper ties with surrounding communities.

An example that might have seemed extreme until recently comes from a town in Hawaii. Residents tapped into their collective skills and resources to repair a flooded-out section of a road when the state’s transportation budget lacked the funding for repairs. Updating the tradition of a community barn-raising, this group repurposed online collaborative tools to identify needed skill sets, coordinate participation, and manage the overall process.

The gaps that drove this innovative effort—both the literal gaps in the pavement and the metaphorical gaps in the budget—point to how a broader level of community engagement is likely to complement, rather than replace, the capabilities and infrastructures of existing organizations. While citizen-built roads won’t become a common means of participation, there will be many more needs met through community-run organizations and systems explicitly designed to supplement strained services. For example, many NGOs are estimating a greater need for volunteer support in 2010 just to provide the same level of service.1

Tapping into this deepening interest in community engagement doesn’t need to ignore the reality of many caregiving situations, including those that require skilled professionals and the dedicated commitments implicit with paid staff. But caregiving systems can grow to include broader participation by explicitly building links between existing institutions and these emerging ad hoc acts of volunteerism. Those institutions that succeed in integrating this new breed of volunteer will be able to allocate specialized resources more effectively and improve the resilience of their offerings during future downturns in funding—adapting faster and with less strain than they would without the expanded community.
FROM RUBY’S BEQUEST: WHAT WE HEARD

“I think that these sorts of networks exist on the internet but because everything will be very local, why not use face-to-face?”

Ruby’s Bequest participant: Moz

The development of Ruby’s Bequest began in Spring 2008, months before the looming financial crises became one of the most impactful stories of the decade. By the time of the launch of the five-week “live” experience in April 2009, it was not difficult for participants to imagine a future where essential services in the ecosystem of caregiving might be widely defunded or cut altogether. Ken Eklund, story architect of Ruby’s Bequest, highlights the power that collaborative scenarios offer participants to “Play the future before you live it,” but many caregivers were already seeing signs of these stresses in their own communities—or at least hearing early warnings of drastic cuts to be made to their state and local budgets in the coming fiscal years. Ruby’s Bequest began as a collaborative experience drawing on the genre of alternate-reality gaming but soon became more akin to an “emergent-reality” game (a phrase coined by designers of a similar collaborative simulation of a pandemic that publicly launched just as fears about swine flu peaked).

With significant challenges to the traditional caregiving infrastructure already pervasive, the first concept to emerge in the virtual town of Deepwell reflected a need for nontraditional thinking. PODCare—an abbreviation for People of Deepwell Care—is a collaborative model for community provision of the common tasks of caregiving, developed by participants of Ruby’s Bequest. It started with the name, posted by Ruby’s community facilitator Gemma Sean writing as her character in the town of Deepwell. She announced the first meeting of townspeople interested in the potential to supplement caregiving needs with community involvement. Gemma built on an early theme from many participants’ descriptions of networking their care across groups in their lives (see Strategy 2). Her recap was deliberately short on details, inviting any who had attended this fictional meeting to step up to share their own takeaways—creating a deliberate narrative “vacuum.” Moz responded to this challenge with a four-point suggestion to divide a geographic area, identify needs and skills, and combine online coordination with existing local networks. This proposed framework quickly became the service’s working model, and the capabilities of PODCare formed a significant core of the narrative canon for Ruby’s Bequest.
EARLY SIGNAL: ALLFORGOOD.ORG

The team behind AllForGood.org describes themselves as “a self-organized crew of software engineers, marketing managers, product developers and designers”—which may represent precisely the new mindsets and fresh blood needed to revitalize volunteering and community participation for the 21st century. Google is the biggest source of hands for this crew, and AllForGood would seem to share a Google’s philosophy that volunteering, like a pre-Google internet, is in desperate need of some smarter tools.

The service connects interested potential volunteers with available opportunities in their local area, consolidating many disparate requests onto the same platform. Even if this were the extent of its functionality, the site would be a valuable addition. But the AllForGood team clearly understands the cross-platform potential of the internet. First, they have integrated AllForGood with Facebook, providing immediate social reward among familiar circles that matter—and creating perhaps the most promising connection between volunteering and the larger web. In addition, users of AllForGood can also create tiny digital “widgets” that rotate through local volunteer opportunities available for anyone to publish on a blog or web site. So volunteer opportunities go viral.

AllForGood is an early signal of how a new infrastructure for volunteering may encourage civic participation initiatives to break out of traditional institutional silos and form connections with existing popular cultures—both online and offline. This infrastructure lays the foundation for more “big ideas.”

Source: http://www.allforgood.org/
STRATEGY 2: RESTRUCTURE CAREGIVING TASKS TO MAKE THEM NETWORKED AND “AD HOC”

Today, caregiving needs are most often met by people whose lives are structured around a dedicated responsibility to provide care. Paid professionals and family members form the backbone of caregiving. But the availability of both sources of caregiving is threatened when families are overworked and traditional services are underfunded or even eliminated.

How can we help over-worked families and under-funded caregivers?

Restructure caregiving tasks for groups of people and ad-hoc volunteers. The growing accessibility and capabilities of tools for networked collaboration are “unbundling” caregiving. Instead of single individuals carrying an often unsustainable burden, caregiving is being networked and peer-produced, adopting the model of open-source systems to distribute ad hoc tasks across a community.

Labor shortages and inadequate pay are creating a crisis in the pool of professional caregivers while budget shortfalls for caregiving services are forcing overworked family members to take on responsibility for more tasks. In this environment, caregivers and recipients of care are repurposing the tools designed for collaborative work or sociality to create new models for meeting their own personal care needs.

Sometimes resulting networks are designed to improve resiliency should something happen to an existing caregiver or service. But in more cases, they’re filling in gaps where no such care is currently provided. While the tools—like mailing lists, wikis, and shared online calendars—are inherently social and easily used for networked coordination, they’re also increasingly real-time to meet the needs of a society that is “always on” and “on-the-go.” Thus the same shared calendar that divvies up a person’s care tasks to his distributed caregiving group can also broadcast alerts via email or send a mobile phone alert if a particular need won’t be met or if new needs arise. As more personal technologies become aware of our locations, this data, too, will be incorporated into collaboration tools, and they’ll get smarter at facilitating real-time, real-place connections.

While there will certainly always be tasks in caregiving that are too critical or specialized to be left to loose ad hoc scheduling, many of the emerging gaps in care can be met by groups working at larger scales with smaller units of participation.
FROM RUBY’S BEQUEST: WHAT WE HEARD

“What if Deepwell could get organized like this on a large-scale basis? What if friends and community members could be matched-up with the needs (sometimes as little as a visit or a ride) of others in Deepwell? What if it was cool for everyone to be involved? What if caring was the new “Green” movement?”

Ruby’s Bequest participant: klinds1

In the early stages of Ruby’s Bequest, many participants shared stories of their own caregiving situations that were already being adapted to the day-by-day availability of a group of friends and family. For example, the network of friends around participant Raven created a wiki to support her care, so they could see “what days [she] had needs [doctor appointments] in their direction.” Tresbien’s network similarly set up a shared Google Calendar to unpack her caregiving needs across the group. And Jess told a story about a bicycling community mailing list that doubled for a time as a channel for coordinating care, repurposing an existing network for this new activity.

The Ruby’s Bequest community facilitation team leveraged this emerging theme of networked care to guide participants towards collaborative solutions built from their shared personal experiences. The primary mechanism for this community learning was the feedback that nearly every story received from at least one member of the facilitation team. These responses often encouraged participants to follow up on their stories of personal experiences with a more speculative submission that abstracted best practices or scaled their own caregiving processes up to a community or neighborhood level. For example, one participant suggested that safety concerns are a significant barrier to innovation in delivering services for seniors, including his/her own idea for senior housing communities. In response, Ruby’s facilitator Maddie introduced the idea of reputation systems to suggest that a similar structure could help address some of the concerns about trust and safety.

The first submission from a Ruby’s participant was often a personal story describing the role and impact of caregiving in his or her life—probably not very different from a first posting shared in an online discussion forum or mailing list about caregiving. Ruby’s Bequest might best be distinguished from these other platforms by this continuous process to grow today’s personal experiences into more broadly applicable ideas for caregiving communities in the future.

Source: http://www.rubysbequest.org
EARLY SIGNAL: GROUNDCREW AND THE EXTRAORDINARIES

The mission statements of two new ad-hoc volunteering platforms, Groundcrew and The Extraordinaries, each suggest that volunteering, in its traditional form, is largely incompatible with modern life, as increasingly hectic schedules leave little time for significant commitments in other areas. From this shared assumption, the projects set off on very different paths to restructure volunteering.

The Extraordinaries is crowdsourced volunteering in the way the term is most often used today: a distributed group of people performing similar tasks to collectively solve a larger problem. Using a free, downloadable application for the iPhone, the service presents users with opportunities for micro-volunteering—many of which can be accomplishable in just a few minutes—working with non-profit organizations around the world.

Some of these tasks can be performed entirely on the phone, such as describing uncategorized photographs in response to a request from the Powerhouse Museum in Sydney. Other tasks build on the geographic distribution and local understanding of the service’s users. Play-advocacy organization Kaboom asks users to scope out their cities and identify undeveloped parcels of land with the potential to be developed into future playgrounds.

Both types of tasks signify a new type of human-assisted machine intelligence that is particularly well suited to subjective valuations that can still befuddle even advanced algorithms. This human-technology hybrid model is especially relevant for caregiving situations that are mediated with presence- and health-detecting sensor systems. (See Strategy 3.)

In contrast to The Extraordinaries, the Groundcrew platform is taking on the challenge of coordinating groups of people in real-time—though still for short bursts of time—to accomplish more significant tasks than any individual could complete alone in a small niche of time. The platform uses a game-like framework of missions, squads, and agents, providing a distinctly different framework for organizing volunteers.

Source: www.theextraordinaries.org

Source: www.theextraordinaries.org
The focus for Groundcrew's founder Joe Edelman is to help existing NGOs and service providers “optimize situations” for ad-hoc group availability. For these organizations—largely unaccustomed to thinking in terms of real-time demand—Edelman suggests a shift in mindset about volunteers in which providers “react to availability, instead of depending on it.” He describes early successes where the Groundcrew platform empowered an organization already serving a community to quickly expand their pool of volunteers by providing an alternative framework for their participation.

Edelman envisions a future of collaborative competitions where participants earn points and status for completing good deeds. He even encourages participating organizations to design volunteer opportunities around fun and heightened engagement, in line with the mission of Edelman’s company to “make technology that changes how it feels to be alive.” For those tasks that are more like typical caregiving needs—those that are personal or health-related—the Groundcrew platform hopes to incorporate flexible and aggregated metrics for reputation, like Facebook friendships and eBay ratings, as a first pass for filtering participants.

One final signal of the potential for distributing caregiving is Microsoft’s Vine service (which is still in testing at the time of writing). It’s designed as a channel for local coordination and information during times of crisis and disaster, but Microsoft’s materials also suggest broader uses of the service to “Be informed when someone needs help,” and “Get involved to create great communities.” Many projects applying connective technologies to emergency coordination are confronting the same challenges that face ongoing caregiving, so the potential for collaboration is high.

Source: http://groundcrew.us
Use incentives that help people feel like they are part of something bigger. In traditional caregiving models, families are motivated by caring, and professionals are compensated with cash. But as Joe Edelman, founder of the Groundcrew platform for real-time locative participation argues, “Cash isn’t that hard to beat.”

As an incentive for engagement in the 21st century, he suggests that caregivers and others who want to reinvigorate participation should look at modern experiences that make people happy and keep them engaged day after day. Indeed the most promising of the current innovations in volunteering all connect individual acts of participation to higher-level systems of recognition, achievement, personal benefit, or collaborative outcomes.

Sociality and game experiences have become so intertwined that, together, the two provide a promising framework for motivating engagement. At the heart of this framework is personal achievement plus social visibility. For example, the system for achievement that is built into Groundcrew’s model wouldn’t work as an incentive if users couldn’t easily see one another’s current ranking.

The one-stop volunteering portal AllForGood.org allows users to login via their Facebook profiles, and uses this ability to build on the engrossing nature of leading socially mediated lives. When AllForGood volunteers finish a task, the service will cross-post a successful completion message to their Facebook profiles. This message acts as a powerful “social object” that gets broadcasted for immediate recognition by their friend networks and endures as a lasting badge of honor for their long-term digital personas.

Even though cash isn’t hard to beat, less tangible forms of exchange actually do work in many of the new volunteer models. For example, one of the most innovative ways to incentivize caregiving is to provide a transparent way for caregiver networks to track time they spend helping others. This kind of time-banking encourages engagement by directly correlating caregiving to one’s own requests for assistance. Charlotte Frank, founder of the Caring Collaborative, has said that time-banking is sustainable “because it’s a transaction, a contract. It’s very structured. That allows people to feel independent, not like recipients of charity.”

Gaming mechanisms offer similar ideas for transactional systems that can incentivize and then sustain participation in new volunteer models. In addition to Groundcrew’s metaphors and mechanisms for adventuring, discovery, and collaborative competition, the platform is also experimenting with more tangible incentives like access to resources in a community that can become communal or traded, including cars, tools, and skilled services.
FROM RUBY’S BEQUEST: WHAT WE HEARD

“There are some issues left with PODCare we could use your help on. PODCare has expanded beyond Deepwell to serve much of the entire county now, and that’s showing some problems.”

Ruby’s Bequest facilitator: Northfork Gary

Creating incentives that can sustain participation was an important challenge for Ruby’s Bequest at several levels. With the shared goal to understand and improve the level of caring in the town of Deepwell, participants considered the barriers that can prevent novel experiments in volunteering or civic engagement from ultimately sustaining their involvement or scaling beyond small trials. For PODCare—the model for community engagement developed for Deepwell by Ruby’s participants—initial ideas for implementing the service leveraged a form of facilitated altruism in which the system worked to match open tasks with the schedules, interests, and lives of townspeople. For example, a neighbor needing a ride in the PODCare service would be paired with someone already traveling that direction.

As the underlying scenario of Ruby’s progressed into the future, PODCare moved from a supplemental grassroots experiment to become an integral part of the town’s ecosystem of caring. An alternative local currency of “Rubys” was proposed to reward contributions of time and services with material goods. The Ruby’s Bequest facilitation team encouraged participants to consider how a town’s growing reliance on community involvement could persist over the longer term. Later dispatches from Deepwell, including the update from facilitator Northfork Gary excerpted above, describe how PODCare scaled to serve a larger area and provide more vital services and, as a result, severely strained the limits of motivated but still volunteer resources. This mixed success stood as the final forecast for the PODCare concept, becoming an open question about how to sustain community engagement.
EARLY SIGNAL:
CARING COLLABORATIVE AND THE FUREAI KIPPU SYSTEM

The fureai kippu experiments in Japan and the Caring Collaborative in New York City offer early previews of what sustainable incentives for caregiver networks might look like.

Japan is a country well known for the large and growing disparity between its elderly citizens and available resources for caregiving. The most publicized solutions to this gap build on Japan's expertise in robotics to replace the need for human labor altogether. But another group is quietly promoting an idea that supplements caring with reciprocally incentivized community participation.

In the fureai kippu model (translated literally as “caring relationship ticket”), participants can bank the time they spend on caregiving tasks to be used for their own future needs. By some accounts, there are 500 communities in Japan practicing some form of fureai kippu, and the Sawayaka Welfare Foundation, creator and overseer of the fureai model, has developed structures that allow earned credits to be transferred between participating communities, helping to scale to the network beyond local communities.

A different take on time banking comes from the Caring Collaborative, which supports a network of women over 50 in Manhattan called The Transitions Network. These women have come together for help with the process of aging. As Charlotte Frank, the founder of both groups, says, “There’s no benchmarking book for getting old.” Frank sees reciprocity as a vital component for sustaining a peer support system and proposes the term “care-sharing” as an expanded update to “caregiving.” But in her view, time-banking fades away as a primary motivator for participants after the system has been operating for a time, leaving behind a deeper culture of caring. (See Strategy 7.)

The Caring Collaborative has begun to work with other existing community groups around New York to create their own time-banking collaboratives, and the Collaborative’s concept of a “vertical village” overlays the model onto larger buildings with multiple residents. The benefits of these arrangements have the potential to improve overall health outcomes and reduce costs across the health system: Ms. Frank cites the example of a member-supported rideshare for preventive colonoscopy screening.

But the most lasting benefit to these new models for care may be a fundamental change in the inevitable process of aging. Ms. Frank describes interviewing a still-active participant in her early 90s who said, “I’m a very old woman, but I still have these buddies,” referring to her fellow members of the Collaborative.
STRATEGY 4: CREATE OPEN PLATFORMS AND DIY TOOLKITS FOR CAREGIVERS TO INNOVATE SENSING TECHNOLOGY

Millions of caregivers and recipients of care are already using free and collaborative online services for social support, research and learning, group coordination, and sharing ideas to improve each other’s lives. The next frontier of technological caregiving will be systems that make meaningful sense of the physical world using sensors, but so far these solutions are highly proprietary and closed to innovative users.

How can we design next-generation sensor technology to leverage innovative networks of caregivers?

Open up sensor systems and make them easy to use. The just-around-the-corner potential of the “smart home” has been a familiar trope for futurists and science-fiction movies for years. Even though these visions promised lives filled with labor-saving automation, practical uses for “smart” sensor-based technologies have been largely overlooked in the areas of health, and particularly caregiving.

Within the past few years, however, this potential has begun to take a real shape. Thousands of people now live in environments outfitted with sensors that continuously detect and report some types of health and behavioral information. Current versions of these systems aggregate multiple data points from relatively simple sensors to form an overall picture of a person’s current health status. On the horizon are sensor systems that will incorporate data from wearable biological sensors to augment cruder presence data and ultimately create more effective opportunities for caregiver intervention.

Sensing platforms face a critical choice that could shape their rate of development and distribution for years to come. This is a choice between proprietary systems that are largely closed to end-user adaptation, and open systems that emphasize plug-and-play compatibility. The open path requires interoperable standards between competing companies and the creation of easy-to-use toolkits for ordinary users. The return is a rich foundation that will allow millions of people over the next decade to make sensor technology as powerful and personal as the World Wide Web.

As effective as technology research labs have been at identifying caregiving needs and creating mass-market interventions, Ruby’s Bequest demonstrated how much technological innovation is already occurring. Not only would flexible sensor systems and simple toolkits allow these technologies to best support individuals in their unique situations; many of these innovations would also likely be very useful to other caregivers if the innovations could be shared.

Increasing the engagement of users in shaping the technology will also surface questions about the impacts of technology on caregiving dynamics more quickly—and lead to faster responses to the dilemmas that are sure to emerge. For now, the ultimate goal of sensor systems is to improve in-person interactions by creating smarter and more targeted opportunities for intervention, when engagement is most needed. But it isn’t difficult to imagine a path where the widespread use of sensors begins to replace high-touch interpersonal care, and indeed the first reports from people providing care for individuals living in a “smart” environment suggest that this shift may already be occurring.

For many caregivers, however, a shift toward smarter and more targeted opportunities for human care may be the best result of sensors for caregiving, while opening up the potential for peer-to-peer and group monitoring and support that would be impractical without the technology.
FROM RUBY’S BEQUEST: WHAT WE HEARD

“Now that it is the year 2015, video conversations are a lot more common, which is a good thing! For some reason I find it a lot EASIER to talk to people via videophone.”

Ruby’s Bequest participant: Sophie C.

Ruby’s Bequest launched on April 16, 2009, but that first day’s narrative date in the fictional town of Deepwell was one year later, April 16, 2010. The design team made the decision to focus the experience on the nearer-term terrain of caregiving—progressing five fictional years over the five-week experience—in part because of the largely untapped potential for existing technologies and services to help caregivers.

Many participants shared stories of how they were already using and repurposing online services and software to support their own networks of care. (See Strategy 2.) With this familiarity in place, the challenge that emerged was less about introducing technological capabilities and more about encouraging participants to combine ideas and scale their experiences up to communities and cities.

The first new service model to emerge from the Ruby’s community, PODCare, was powered by location-aware mobile devices and “lightweight” social software like wikis and group calendars.

As the Ruby’s scenario continued into a narrative timeframe of 2012 and beyond, the facilitation team began to introduce the opportunities and potential dilemmas of less familiar technologies that will have a significant impact on caregiving. To provoke participants to consider the role of sensors in the caregiving environment, the team developed a visual provocation in a format IFTF calls “artifacts from the future.” Such artifacts are illustrated forecasts that suggest how technological and societal trends can impact familiar domains. In this case, the artifact was a mobile phone display indicating that an elderly townsperson in Deepwell had been sitting in her “smart” recliner for over three hours without getting up to move. In addition to presenting the raw data itself, the mobile phone asked if its user would like to call the woman. This image, in combination with a more detailed explanation, was designed as an accessible introduction to the near-term capabilities of sensors—detecting presence and activity in this scenario—and a subtle provocation about the potential for de-personalization as caregiving interactions become increasingly mediated by technology.

In contrast to the ambiguity embedded in this artifact from the future, an anonymous participant submitted a video link from YouTube for a concept video from Microsoft about the “future of personal health.” The day-in-the-life video is an elegant vision for the increasing role of information and communication technologies for managing personal health. While it expertly succeeds at conveying new functionalities for health technologies, it leaves out any signals that might invite most viewers to consider these developments in a more holistic—or even explicitly negative—context. Given that the scenario comes from a technology company, this missing layer isn’t a surprise. But it does reaffirm the need for independent platforms and processes that both provoke discussion about the range of technological impacts on society and also reward participants for suggesting constructive solutions to imagined problems.

Source: IFTF, 2009
In the AARP Health@Home survey of their membership conducted in 2008, 87% of respondents indicated that they would prefer caregiving in their homes and would be willing to give up some privacy to make that possible. This finding isn’t new or surprising, but creating effective in-home care delivery has been difficult. Centralized, live-in centers are often the only way to achieve the efficiencies needed to make caregiving economically feasible. Nevertheless, the potential to provide or supplement care in the home—the so-called “aging-in-place” strategy—will likely be realized in the next few years as companies, products, and services rush to tap this large market.

The most ambitious aging-in-place initiative to date was announced in April 2009 as an alliance between G.E. and Intel to research, develop, and market “home-based health technologies,” beginning with joint distribution of two existing products: Intel’s Health Guide for doctors to remotely track patients with chronic diseases and G.E.’s QuietCare sensor-based system for basic activity monitoring in the home. The announcement of the alliance and the $250 million investment garnered significant press coverage and speculation about future smart homes for aging, but some analysts reported that they were “underwhelmed” by the funding and the apparent lack of commitment it represented.

Laurie Orlov of the Aging in Place Technology Watch blog suggests that this alliance is meant to be a gradual investment with a slow start that will scale over the next decade as the caregiving needs of the baby boom generation demand more involved offerings. Orlov sees a new industry perpetually in waiting as she analyzes the current aging-in-place innovations, noting that technology companies are not recognizing and responding to the existing market of seniors and caregiving organizations that put these products to use today. She’s even coined the term “YARC”—for “Yet Another Research Center”—to convey her lack of enthusiasm announcements of new academic-industrial partnerships to develop technologies for aging. To Orlov, these centers operate without any perceivable near-term pressure to convert research into marketable and usable deliverables, which is clearly a loss for anyone who could immediately benefit from the promise of new functionalities.

Technologies for aging in place are particularly well suited to the model of open platforms and a generalized philosophy of co-collaborative development with users. The baby boom generation keenly understands the transformative potential of technology, and while they may not yet need the solutions for their own aging needs, millions of boomers around the world are already providing care for aging parents today. Packaged systems like G.E.’s QuietCare are designed for the commonalities across caregiving contexts, but every caregiver’s routine is made up of individual needs, settings, and habits. Flexible, easily customized toolkits for sensing health in the home would allow caregivers to create configurations that work best for them, and open platforms powering these systems can catalyze a community for caregivers to share their adaptations for others to use and grow.

Source: http://www.ageinplacetech.com/
Leverage aggregate patterns of caregiving to create new measures—and stories—for “communities that care.” A new era of technological mediation of caregiving is underway with the adoption of online networks, group scheduling, real-time volunteering, and ubiquitous sensors. Such uses of technology will add layers of quantifiable data to many caregiving situations, even at the individual level. This data can be aggregated and scaled, creating new indicators of caring across organizations, communities, and even regions.

Imagine a scenario, where dedicated caregiving responsibilities have been redistributed across networks of people and geographic areas and segmented into discrete tasks and shorter volunteer opportunities. The completion rate of these tasks could become an immediate measure of caring, scalable from one neighborhood hour-by-hour to a metropolitan region over weeks or months. If these indicators were to achieve any kind of permanence, we could imagine that local measures of caring might become a component of overall livability, leading to the kinds of competition among cities and regions that we’re starting to see today with the emergence of sustainability ratings. A key question here is: what will be the best indicators of caregiving in this highly instrumented world?

Multiple measures of care will emerge: some will be derived from traditional authorities and infrastructures but many others will be scaled up from grassroots reporting of data. Demands for transparency will be an important driver, not to be underestimated. Care facilities that incorporate networked technologies or sensors in the name of efficiency can expect to be petitioned for access to their data by families and engaged communities who are concerned about quality of care. Open systems would make such data immediately actionable. Within the next decade, it’s possible that a care facility might be continually monitored and evaluated based on, for example, an aggregated, median duration its patients have been immobile as determined by cheap embedded sensors in beds and chairs.

Quantified caregiving will also power intelligent, actionable visualizations that dynamically respond to new data. Early examples of these already exist in the “dashboard” interfaces for nurses who remotely monitor the vital signs and daily self-reports of large groups of patients. As more individuals, peer groups, and families are able to incorporate caregiving technologies into their own contexts, an abundance of personal displays and indicators will provide caregivers with an at-a-glance or unobtrusive understanding of a person’s health and well-being—enough information to settle that undercurrent of worry caregivers speak of in the absence of information.

With 7 million people in the United States responsible for the care of someone more than 1 hour away, and many millions more living far away from parents and family they are concerned for, any data indicating a loved one is alive and healthy at that moment will be a story that can change many caregivers’ lives. But these stories will add up to more than individual reports of well-being. Today we see a growing willingness of patients to share their health data in online communities like CureTogether and Patients Like Me. The goal of these sites is to provide individual support for patients while aggregating data that could be useful to the group as a whole. We can imagine that these models of personal tracking systems that also add up to insights for the entire community could emerge in the broader arena of caregiving.
IN RUBY’S BEQUEST: WHAT WE HEARD

“Everyone could see at a glance how well people are being cared for and pitch in where needed.”

Ruby’s Bequest participant: Tresbien

The bequest that sets in motion the events of Ruby’s Bequest came with some strings attached. For Deepwell to actually take payment of the money bequeathed by the mysterious Ruby Wood, the newly dubbed “town that doesn’t care right” must improve its “level of caring” within 5 years, ending in 2015. Defining such a nebulous metric was the responsibility of the law firm charged with executing Ruby’s estate, and their solution—the Deepwell Caring Index, or DCI as it became known—exemplifies a potential for improvement measurement and greater transparency in caregiving, but also a narrowly procedural definition that could limit broader solutions.

The DCI served as a collective measure of engagement with the topic of caring for both the townspeople of Deepwell and the real participants of Ruby’s Bequest. But updates to the Index—mapped onto a scale of 0 to 300—weren’t fully transparent to either group, whether announced as an intermittent phone call to Deepwell from the law firm or as an update on the home page of Rubysbequest.org.

The Ruby’s design team considered a more direct correlation between the Index and the actions available to participants, including registering with the site or submitting new content. In this approach a participant could have seen a small but detectable increase in the DCI immediately after sharing a story or idea. Similar platforms have successfully used collective measures to motivate participation: they help participants visualize an individual contribution to a greater goal.

For Ruby’s Bequest, an Index that functioned more like a “black box” was a decision about flexibility. The design and facilitation teams used it to seek out new types of participation as the five weeks of the project progressed. Each adjustment to the DCI was signaled by a clarifying explanation from the law firm; the Ruby’s team used this vehicle most often to encourage broader consideration of topics within the whole ecosystem of caregiving. Or they used it to direct participants to connect by building on one another’s ideas.

Building an index of caring from these forms of engagement—broader systems thinking and iterative collaboration—was not originally intended as a forecast about the future of quantified caregiving, but it does suggest an approach that future metrics may wish to include. A town’s index of caring in 2015 may be comprised of previously discussed inputs like real-time sensor readings; but it may also incorporate less obvious data, such as transportation timeliness or even new online friendships forged between residents on a network like Facebook.
Early Signal: DIYCity

Any index of caring in 2015 will be significantly helped by efforts like DIYCity. Founder John Geraci defines a DIYCity as being “like the Internet in its openness, participation, distributed nature, and rapid, organic evolution.”

In the DIYCity philosophy, what makes existing cities closed and non-participatory today often starts with access to municipal data. Geraci sees cities today as “just giving off data,” from static databases that list the locations of planted trees to dynamically updated feeds of bus arrivals or daily reports of tuberculosis. When civic data is unavailable to the public, the reason is most often that cities just aren’t aware that their residents could benefit from it.

Much of the work of DIYCity is about creating this awareness and gaining access to data, and the movement Geraci catalyzed has contributed to large initiatives like the expansive data portal San Francisco recently created at DataSF.org. San Francisco mayor Gavin Newsom publicly touts this effort as contributing to San Francisco’s local economy, citing examples of new companies that have built services and software from newly opened data sets.

Chapters of DIYCity meet on five continents and dozens of cities. Their usually tech-minded members push for greater access to local data and collaborate together on new ideas to make the data meaningful or profitable. The central portal for the DIYCity movement also hosts pan-geographic thematic challenges like SickCity, which is an effort to create an open infrastructure for grassroots citizen mapping of infectious diseases.

Geraci speaks of efforts like this as “improving the resiliency” of cities as more residents outside of government understand and get engaged in civic processes. He sees a lot of potential for data sets to be combined and tell stories about CaringCities, with the hope that as caregiving creates new feeds of data in the coming years—from the on-time ratings of paratransit systems to the sensed activity by residents in a care facility—this data will be open and accessible from the onset.

Source: http://diycity.org/group/sickcity-development

Source: http://data sf.org/
STRATEGY 6: INNOVATE ACROSS DOMAINS

Caregivers provide for the urgent needs of some of society’s most vulnerable populations—often with the fewest resources and opportunities to innovate solutions. Yet these populations often have the highest need for innovations—social, medical, and technological.

How can caregiving tap the stream of global innovation?

Build links to innovation networks across domains to break out of the caregiving silo. Much of the innovation in open-source solutions, networked services, and crowdsourced innovation is occurring outside the walls of traditional caregiving institutions—and also seemingly beyond the reach of family caregivers. While we might hypothesize that the urgency of their needs would drive caregivers to be lead innovators, this has not proven to be the case. Nevertheless, caregivers could become so-called fast followers by deliberately hooking their collective carriage to platforms and processes that tie them intimately with other, and perhaps unexpected, domains.

For example, the knowledge and resources necessary to provide innovative solutions for caregiving are spread across a disparate range of sectors, institutions, and disciplines. One of the advantages of the kinds of distributed caregiving networks represented by platforms like AllForGood, Groundcrew, and the Extraordinaries is that they attract people from many different domains and create a venue for emergent cross-pollination of innovative ideas. Could a volunteer who just happens to be working on the problem of distributed transportation solutions for her day job have a life-changing insight into ways to organize distributed meal preparation? With new network strategies, caregiving organizations have the opportunity to leverage brief encounters with people and organizations from all domains to spark a kind of “combinatorial innovation.”

Such innovations could also spring from more intentional cross-domain relationships. It’s often difficult for caregivers to reach across the boundaries of commercial vs. nonprofit, of national government vs. local community, of church vs. state, or even of lay vs. professional. Yet the opportunity for alliances across these boundaries—for networks that deliberately span the different charters and scales of institutions—has been demonstrated, for example, in the world of global development. Here tri-sector alliances (government, corporate, and NGO) are demonstrating success in meeting the development needs of impoverished populations where previous efforts by the individual sectors have failed.

One of the barriers to this kind of cross-domain collaboration has been the prejudices that each domain harbors regarding the others, and one of the hypotheses that arises out of the experience of Ruby’s Bequest is that the anonymity of online networks can reduce this barrier. When people come to a town like Deepwell, they leave their institutional identities and credentials at the town line—and with them, their judgements about whose ideas and solutions might be more or less valuable, more or less accessible, and more or less welcome. So a design strategy that anonymizes participants (or at least their affiliations) might actually lead to better opportunities for innovation.
**FROM RUBY’S BEQUEST: WHAT WE HEARD**

“If professional caregiver organizations create the buffet it will be stocked with what is best for me. If me and my community of users create the buffet it will contain what I want and will probably be used more frequently, efficiently, and cost effectively.”

*Anonymous Ruby’s Bequest participant*

Establishing *Ruby’s Bequest* under the banner of caring very likely opened participation to people who would not have contributed to any effort related to caregiving. Some would have found no interest in a topic seemingly unrelated to their current life stage or situation. Others might have actively avoided a topic that can carry a sense of burden.

For example, dr00_1138 was a young participant who originally expressed this sentiment: “When you’re a kid, it sometimes feels, oh please don’t kill me for this - a little unfair to be expected to care, when there’s so much other stuff to worry about.” But he went on to say that, “When stuff is less like a checklist, and more like a really needed thing, kids will understand. (And that’s why I love the podcare stuff, personally, but I was shy at first!)” This young participant was underscoring the natural “sympathetic joy” that comes from participating in something larger than oneself to meet the needs of others, but also the value of building a platform that reaches across communities of identity—in this case, across generations.

In such platforms, identity management is an important consideration. In *Ruby’s Bequest*, there was no provision for participants to create personal profiles that would allow the community to know where they lived, who they worked for, what they did for a living, or how they were trained. Their identities were encapsulated in a name and a simple icon. The only “credentials” they had were the stories of caregiving they shared. But in fact, participants in *Ruby’s Bequest* actually did represent all different kinds of organizations, large and small, public and private, religious and secular. So the innovative thinking that emerged from the game was itself the product of a cross-domain conversation.

Some of the organizations, large and small, represented by participants in *Ruby’s Bequest*:
- Acess and Participation Programs (WA)
- American Dental Association
- Cessi.net (Accessible Solutions)
- COSI (Columbus Ohio Science and Industry)
- Costello Consulting
- Deimara Foundation for Aging and Disabilities
- Direct Care Alliance
- Episcopal Church
- Event 360
- Family Voices of MO
- Games for Change
- Hallmark
- Healthwise.org
- Herman Miller
- InterAct for Change (Philanthropy)
- Late Life Care Innovations
- League for People with Disabilities
- League for People with Disabilities
- Lifebridgehealth
- Love Makes a Family
- Maui United Way
- N. Power PA (tech assistance)
- Ohio State University
- Ovos Design Group (Austria)
- Procter & Gamble
- Sacramento Metro Chamber of Commerce
- Sonnenschein Nath & Rosenthal LLP
- Spin Inc.
- U.S. Centers for Disease Control
- U.S. Department of Energy
- Virillion (interactive digital media)
- Well.com
- Worchester, MD, Board of Education
Two innovation networks provide models for using cross-domain expertise to address social problems. The first is Think Cycle, which was piloted at MIT as an open-source engineering design platform to solve “real-world problems.” NGOs were invited to submit challenges to the community, and design students and practicing engineers would work together in collaborative “cycles” to come up with solutions to the problems.

More recently, Challenge Post has combined the idea of a crowdsourcing platform for solving problems across many domains with micro-financing. On the Challenge Post website, people post challenges in categories that range from Education and Environment to Health, Household, and Food & Drink. Others sign up to support a challenge, pledging small amounts of money that can add up to big prizes for a winning solution.

It’s easy to imagine that caregiving networks like the PODcare network envisioned in Ruby’s Bequest or volunteer networks like Groundcrew could extend their own services to include innovation challenges for caregiving. Or they could link to marshall their memberships to support challenges on open challenge sites like Challenge Post: imagine the amount of money that could be raised for an innovation challenge if everyone who participates in Groundcrew also pledges $25 to support it.

Or these caregiver networks could also engage in more emergent forms of innovation by linking to platforms like CureTogether (see Strategy 5) to aggregate bottom-up experiences with therapies, treatments, and care regimens. For example, in CureTogether, some people are tracking the impacts of a variety of interventions related to aging. By cross-pollinating such networks, caregivers and volunteers can rapidly create new sets of best practices, often simply by doing things they would be doing anyway, such as tracking the daily status of someone they care for.
Integrate caregiving tools and social practices into the existing infrastructure of our shared daily lives. Several notable innovators working on the now inextricable challenges of volunteering, participation, and community involvement seem to recognize the current transformative potential within civil society in the United States and around the world. Joe Edelman ascribes a “global mission” to the Groundcrew platform to “create face-to-face community on an unprecedented scale.” Charlotte Frank, founder of the Transitions Network and the Caring Collaborative time-banking system, described her goal in less dynamic but equally transformational terms to create “a culture of caring.” Both of these visions suggest deep-rooted ties between and amongst neighborhoods and communities that will be formed and sustained by the emerging tools, challenges, and values of 21st century life. They also suggest a fundamental shift from a model of individual caregiving to a society that incorporates care into the fabric of the daily lives of everyone.

Imagine what a 30-minute span of daily life in the next decade might look like with a lens of caring: A man stops on his commute to clean the house of a fellow parishioner across town hobbled after surgery, banking each minute spent for his own use in the future. While they chat, the recovering parishioner is keeping one eye on his laptop to monitor a stream of health and activity data for an elderly neighbor, gently prodding her to go for a short walk but ready to act if her indicators suggest anything is amiss. Nearby, two college students are meeting up to deliver meals to a few neighbors. They each had a half-hour free, saw a challenge posted within a few blocks from the local food bank, and thought it could be a cool way to meet new people—plus it earns them a free hour in the town’s car-sharing system and boosts their reputation on Facebook. And very likely, none of these people would label their efforts as caregiving nor would they adopt an identity of a caregiver.

These visions don’t call for any fundamental reorganization of mainstream structures and living arrangements. Notable across the current crop of innovations for volunteering and participation is a heightened sense of pragmatism—an understanding that any new solution will need to adapt to current social structures and not the reverse. While the next decade could see some significant return to communal living arrangements, particularly as boomers redefine the norms of retirement, it will be this adaptive reorganization of our present lives that will create the opportunities for a culture of care.

A shift towards broader systems of caring could also realign traditional patterns of who provides care. The gender disparity in familial caregiving situations is well documented, with estimates ranging from 59% to 75% of such care provided by women. But a redefined and expanded notion of caregiving could reduce the barriers to getting men involved. This rebalancing will also be influenced by the significant gender disparity in recent layoffs: 79% of those laid off since December 2007 have been male, leading University of Michigan economist Mark Perry to dub it the “mancession.” With many men removed from the full-time workforce, they may find themselves free to engage in new ways with caregiving.

If caregiving services are to meet the needs of aging populations in an era of fewer financial and labor resources, they may find themselves with no other choice than to reshape themselves and their surrounding communities into broader cultures of caring. And the innovations discussed here and inspired by Ruby’s Bequest point us to the path of change as well as the vision of such a culture.
IN RUBY’S BEQUEST: WHAT WE READ

“I think one has to take good care of caring. To care for someone unknown is a different thing and must be practiced.”

Ruby’s Bequest participant: PinkCloud

Throughout the stories in Ruby’s Bequest, participants regularly move beyond the practical strategies for making sure specific needs are met; they also reflect on the larger questions of what it means to be in a community that cares, what it takes to build that community, and what happens when communities aren’t engaged in caring.

After listing many practical ways that people can connect to share the tasks of caregiving, especially in a poor economy, participant Jan says: “Dealing with any challenge alone will be unsuccessful, it is the lone sheep that is devoured by the wolves. Find others and stay together sharing, supporting, and watching over each other.”

After sharing an insight about how to discover the right way to help someone you care about, bkreit raises the larger question: “How can we move from understanding what the people close to us need to helping people we don’t know well?”

And Jane Phillips sums up her experiences of caretaking with two lessons that go to the heart of a caring culture: “The first thing I learned was that I got back more than I gave in caring for my loved ones. The second thing I learned was not to be selfish in caring—to let other people in to enrich their lives through caring also. In a caregiving situation, it can be easy to isolate yourself from others, just because day to day demands keep you so occupied and the structure of your day has its own kind of comfort. But on reflection that’s a dangerous way to go—it deprives the one you are caring for of the love that others give and it deprives you of the same thing. The future of caring is in community—reaching out and letting people in on every level.”

The Ruby’s Bequest community was stunned by a real life story of a “town that couldn’t care right” during their collaborative experience. The report emerged from South Carolina, where a 72-year-old widow died in her home and no one noticed she wasn’t around until 18 months later. The story reminds us that no matter how effective we are as individual caregivers with individual friends and family members who need our help, we won’t solve the problem of becoming a town that cares without engaging the larger community in acts of caring, in a culture of caring. If the widow from South Carolina had lived in the kind of world imagined in Ruby’s, she might not only have been discovered sooner, she might actually still be alive—contributing herself to a network of caring.
EARLY SIGNALS: PARTICIPATORY BUDGETING AND TRANSITION TOWNS

The same kinds of social and technological innovations that could transform caregiving into a culture of caring are already changing the cultures of communities worldwide to address other pressing social needs.

For example, time banking is part of the scaffolding that can create and sustain a deeper culture of caring, providing a framework for participation. (See Strategy 4.) Already we see signs of this new willingness to participate in “caring” for communities with the spread of participatory budgeting initiatives. While the participatory budgeting movement started in Porto Allegre, Brazil, it has spread to communities all over the world as a way to more equitably distribute limited resources. Recently, the city of Santa Cruz, California, added social media to the mix to speed its budgetary decision-making in the face of massive budget shortfalls across the state. The process, and similar efforts across the globe, signal a shift in the readiness of people to take an active role in their collective well-being.

Similarly, in the face of energy and climate crises, towns and cities are working to transform their daily lives to create a culture of sustainability. For example, the Transition Towns movement is a worldwide bottom-up movement to “engage people in forming local groups to look at all the key areas of life (food, energy, transport, health, heart and soul, economics and livelihoods) with an eye to mitigating the effects of carbon and adjusting to dwindling oil supplies.” Using social media like wikis and forums, they have helped to shape sustainability platforms for cities from Portland, Oregon, to Denver, Colorado, to Hohenwald, Tennessee, and Hancock County, Maine. Such initiatives are rapidly creating a culture of sustainability, but “What if,” as Ruby’s Bequest participant Klinds1 asked, “caring was the new ‘Green’ movement?” How does a community “get organized to care”?

If these early signals are any indication, part of the answer is that they set up social networks and tools that help them begin to reinvent the details of daily life—just as they did in the fictional world of Deepwell and Ruby’s Bequest.

Source: http://santacruz.uservoice.com
**APPENDIX 1: PARTICIPANT PROFILES**

At the conclusion of the *Ruby’s Bequest* project, IFTF conducted a series of ethnographic interviews with participants, aiming to capture some of the more qualitative experience of participants with *Ruby’s Bequest*. Below are excerpts from these interviews with five lead participants.

**Joe Kornowski**

Works for Lexis Nexis. He works a lot at home, and had been a family caregiver for his wife for six years. He’s interested in consciousness and healing, and blogs about comprehensive approaches to caregiving at [http://integralcaregiver.com/](http://integralcaregiver.com/)

**INTRIGUE OF RUBY’S BEQUEST**

“What led me to try it out was a couple of things: For one, the concept was very intriguing to me, so I wanted to try it. I wanted to figure it out and see if I could figure it out, at what level I could engage with it … So a little bit of it was my own curiosity and intrigue and desire to engage on the subject matter. Another element of it was that it was something that I had not encountered before, frankly, so in that sense, I had sort of my professional curiosity hat on and thought, well, this is interesting. How does this work and what are the parameters and the dynamics? … So it was really from both perspectives—both from a strong desire to engage on the basis of the content and the goals of *Ruby’s Bequest* and also trying to understand this kind of a role play game kind of format for doing this kind of thing.”

**GAMES WITH A PURPOSE**

“I’ve sort of thought about getting engaged in things like *Second Life* and *The Sims* and things like that … but they just don’t really have the—and especially given my other challenges and obligations with my time and resources—just haven’t been compelling enough. They were too much game. I guess that’s one way to say it. If it’s a game for game’s sake, it’s not as interesting to me as game in the context of trying to solve a real-world purpose and trying to do some real forecasting and thinking through about potential issues that are serious and have policy implications—that to me, is what made it interesting.”

**ENGAGING WITH THE SITE**

“It took me a little while to get oriented. So I had to work a little bit at figuring out how this really worked … trying to pick, how am I supposed to engage? When I do engage, what’s the proper or appropriate point of view or voice, knowing that these are posted “stories” or sharings or aspects of the narrative that collectively is being created? Trying to figure out, how do I position that? Do I talk in total real-world context, do I talk in the framework of the game and its assumptions and the metaphors it’s created … so that took a little bit of thought to try to figure that out. It also took a little bit of work to figure out how to do some of those things…So in terms of the site layout, it wasn’t as intuitive or clear as maybe it might have been exactly where to start, how to get oriented. It wasn’t a step one, step two, step three. It was more right brain, I suppose.”

**Integral CG | Santa Rosa, California**
Donna Foote works five days a week as a waitress. She lives in a two-story house with her husband and her three daughters. One daughter, Michelle, is a 23-year-old with cerebral palsy. Donna’s husband is her daughter’s full-time caregiver, with help of her two younger sisters. Donna has never participated in an online community or game before.

ON ENCOUNTERS WITH THE SYSTEM
“She’s [Michelle] been in the healthcare system since she was born ... she stayed in the hospital right away, she’s had a lot of surgeries, she’s been out of town for therapy ... she’s pretty much had surgery from head to toe ... her first one at three months, so ... a lot of the medical, and then a lot of medical really led to a lot of financial.”

FIRST EXPERIENCE OF ITS KIND
“It’s the first time—I’m not much for the computer ... I don’t really have a lot of time either. When they ask for a story, it’s not hard to think about because it’s something that’s already happened before, so it’s right there, you know.”

ON READING OTHER PEOPLE’S STORIES
“It was really interesting to read a lot of the other stories on there ... it kind of helps you to see where other people are, too. It gets the thought out there that caregiving isn’t just for seniors. There are a lot of people who go their whole life with it.”

EXPERIENCE OF THE SITE
“I always had more time on my day off than I would after work. I’d always usually check in the morning and see if there were new stories, or I’d check when I’d get home and see if there were new stories. My day off, I’d visit for quite a while—at least maybe two hours on my day off ... it’s time away from the family and I understand that, and if it wasn’t so important to try to do something to help, then I wouldn’t let that time go away from my family, you know what I mean?”

* This is a picture of Donna’s daughter Michelle who has cerebral palsy and relies on the care of her two sisters.
Jan | Tucson, Arizona

Jan Pavis splits her work time between her job at Walmart and her work for Easter Seals Blake Foundation as someone who helps people transition from group homes into mainstream society. She has been in this field for 11-12 years. Previously, she was a job coach for persons with disabilities as well as in direct care as a professional caregiver. She has a son, aged 25, who is a cancer survivor, and she has cared for him as well. Currently, her son is healthy. She blogs at www.grouphomesupport.com, but has never participated in an online experience like this before.

CREATIVE OUTLET

“I was so impressed with the ideas and the creativity of it, too. I really thought that was pretty cool … This was my first time in an online experience … it was pretty neat … I would always start out with the stories. I liked to read other people’s stories, and then I would go to the blog. At first I just read it, then thought about some ideas, then I would come back and submit it.”

FILLING IN THE GAPS: ALTERNATIVE CURRENCIES

“It was better than I expected because it went more in depth than I expected and the submissions covered a big range, and were a lot more creative than I thought. Like sharing the rubies in exchange for services; like a bartering kind of thing. I thought that was an excellent idea … Something similar we had actually tried to do for the Blake Foundation with child care; especially because it’s 24-hour-care, some people would have a little bit more trouble getting more affordable child care, and they were trying to get a rate where people could exchange child care with one another so they were trading hours and stuff and trying to match up people with different schedules so they could watch each others’ kids and try to help out and match up people who lived close together …. I thought it was a good idea because it eliminated the money issue. If you’re watching your own kid, adding a couple more isn’t that big of a deal, especially when you can go to work and not worry about your child.”

DESIRE FOR POST-GAME NETWORKS

“Submitters might be able to—people could have the option if others wanted to contact them—so like, if I read someone’s article or their submission, I might want to talk with them more about it or get more ideas or something from them. And you know, people can say, yes, you can contact me, or no, you can’t contact me for those who don’t want to. But I’m thinking for those who might want to contact each other and create some networks out of it, I think that would be a helpful thing.”
David Porter is a person with a disability, living with a brain tumor since 2007. He has been medically terminated from his work, but before that, he was a Senior Manager in Business Development for Lockheed Martin Space Systems. His background is full of civic engagement, including volunteer teaching in schools, 4-H, and Junior Achievement. David also understands multi-generational caregiving, as his parents-in-law are reaching old age. He is experienced in war scenarios through his professional past, as well as through playing Dungeons and Dragons. David spent more than 20 years writing government simulations and war games for the military and intelligence community, mainly for their command and general staff school in the Air Force and the Army.

WHY ENGAGE WITH RUBY’S BEQUEST?

“When I came down with the brain tumor, I had serious seizures. And my community of friends and coworkers came out of the woodwork and basically fed me and my wife, and drove me to radiation treatments daily and other medical appointments … I got into Ruby’s Bequest because I get awfully tired of sitting here staring at four walls on a daily basis … I can’t think or explain things too long because my tumor is in Broca’s Area which covers generation of speech and logical arguments and things like that so I can’t do any of my work that I had been, being permanently disabled. And I wanted to find out something I could give back to the community. I can’t be around large crowds because I’m immunocompromised.”

MAKING THE SITE BETTER

“As a participant, I had the problem of how to link up stories … if the story inspired me—as me, or the character—how to link that one with what I’m going to say. I never did figure out well. I could read everything, but I couldn’t link conversations well … I think the game may have been too short to bring feedback to the players about what was working and what wasn’t.

A delta system (early days of war gaming before computers) they gave generals boxes with knobs, and none of the knobs were labeled, and you experimented and saw which direction your goal went, and the knobs were interrelated. There wasn’t a single success—when you cranked one up and cranked another up—they might aid each other for a point and then subtract from each other, depending on the relationship. An example was if you increased the accuracy of your weapons, you had to increase the speed of the logistics to get ammunition toward it, or you’d run out of ammunition and lose the battle even though you had better weapons than you did before. And I say none of these relations were clear to the generals—they just had blank knobs. It’s called a Delta System when you change these knobs. And Ruby’s Bequest was kind of the same way—you had knobs to crank, but I don’t think there was sufficient time to get feedback of what your knobs were doing. And if the point was just caring ideas that was one thing, but the game gave the impression you could have an effect as a player. I don’t think the feedback loop was quick enough to engage game players.”
Derek McCracken, is Creative Director at Hallmark Everyday Editorial. He lives in Kansas City and has volunteered with a Kansas City-based League of Volunteers, Metropolitan Organization to Counter Sexual Assault, Safe Inc. (AIDS housing in Kansas City), Lymphoma & Leukemia Society’s Team in Training.

PART OF A FAMILY CAREGIVING TEAM

“My father was diagnosed with lung cancer … this is probably the turning point in my entire life that very much mirrors my experience in Ruby’s Bequest … It wasn’t up to any one of us to do everything; it was up to every one of us to do something, and we didn’t feel overwhelmed … There was a greater need, and that’s how we [my siblings] came together … We actually use the word team quite a bit … Everybody did what they could do.”

SHARING EMOTION: WHY DEREK GOT INVOLVED WITH RUBY’S BEQUEST

“I’ve worked for Hallmark Cards for 13 years, and so part of our mission to be more relevant to more people more often plays itself out in the realm of caring … A lot of our products have to do with sharing emotion—uplifting someone, affirming someone, comforting someone, and I think every card or gift that’s given helps us do that.”

EXPLORING

“I considered it very exploratory, so when I logged onto the site from home, I started just exploring different areas … There was a certain almost aura of mystery about—I couldn’t figure it out exactly because it really wasn’t like anything I had done. I’m not a big gamer, so I don’t play a lot of video games, but I read voraciously—books, magazines, and online—so to try to get to the heart of something was very important to me. And so when I started reading some of the blogs and peoples’ stories—even though I didn’t know 100% what it was about, I could feel the tone of it … [it] felt very supportive.”

SLOWING DOWN TO TELL A STORY, READ A STORY

“I think what it does for me is it forces us to slow down just a bit, and to even pause and reflect, because from the moment I wake up to a radio broadcast, I immediately go in, turn on the television … So suddenly I’ve gotten information from four sources … What I noticed about things online … I wanted to contribute, could just relax, reflect, contribute at it, go around someplace else … and the tone was very important to me … I thought the content of the site was deep enough that you could stay there for a long time, or if you wanted to just dip in and get out you could do that, too.”
With each story that a participant may read, they also have the opportunity to respond to it. The trails of collaborative storytelling are then recorded, so that you can see which story inspired a given story, as well as the stories that it (in turn) inspired. Below is an example of collaborative chain from *Ruby’s Bequest*. It involves five stories that embody diverse topics and storytelling dialogs. In the next decade, IFTF forecasts that these types of collaborative, open platforms for finding solutions will proliferate and help to categorize both collective wisdom and action around key issues.

*See the 5-story collaborative chain:*

![Collaborative Chain Diagram]

**STORY 1: RHYTHMS OF CONTACT AND CARING**

**Dialogue:** Caring From a Distance  
**Topics:** Daily routines, connection, lightweight caring

My husband’s parents live 1500 miles away. They are in their late 80s, but they’ve lived careful lives and are still able to conduct healthy lives in their own home. For at least the past five years, we’ve had nightly phone conversations with them. It started in a period of crisis for them, when they were dealing with in-home care for one of their own parents. We felt that they needed daily emotional support, a time to vent their frustrations or talk about solutions to things like how to grind food with arthritic hands.

When Grandma passed on, we continued the daily rhythm. Without the drama of that time of crisis, the conversations quickly “deteriorated” into routine exchanges about the weather, what we had for dinner, little errands in the day, what was happening on a favorite television show. We had some discussions about whether we should continue these little calls everyday, whether it was necessary. And we even took a couple breaks from them …
STORY 2: CHOOSING

Inspired by: STORY 1

Dialogue: Everyone Cares for Someone

Topics: Caring vs. Enabling

That's the thing sometimes about caring. It is not all the time so easy to know whom to pick. Sometimes doing caring things can actually be called ‘enabling’ helplessness. I think you have to stick with what your intuition tells you, but be ready to listen to other input just in case.

STORY 3: HIERARCHIES OF NEED

Inspired by: STORY 2

Dialogue: Everyone Cares for Someone

Topic: (ROI) Return on Investment for Caring

Who do we pick? If there is so much need, then what do we do? Is there a way of creating some sort of hierarchy of need? If not, then how do we prioritize the need? Do like in the ’08-’10 recession and only move on things/projects/meeting needs that are “shovel ready?” That sure had mixed results ...-

I’ve spent so much time thinking about what needs are the most dire ... I guess now I’m finding myself asking what needs are the most promising. I mean ... what are the needs that people have that, if we made a difference or invested in trying to address them, there could be a disproportionate payoff?
STORY 4: TIPPING POINTS

Inspired by: STORY 2

Dialogue: Everyone Cares for Someone

Topic: Community Gardening, Big Change, Tipping Points

... it is amazing what one can accomplish with small amounts of effort and some raw optimism alone. It also helps that you sort of feel trapped. We were poor artists and couldn’t afford a better neighborhood at the time. In a way this situation we’re experiencing in Deepwell then is just that limitation we may need to get us into ‘action’ mode.

Giddy up everyone!

STORY 5: CARING FOR A TOWN

Inspired by: STORY 4

Dialogue: Stories From the Trenches

Topic: Long term care, trees, community, tipping points

I liked Marti’s story about the “tipping point” of her street in Chicago. I live in Brea, CA, in the Los Angeles area, and my husband and I have a very similar story. Except ours involved planting trees and taking care to water them (and replace the one that got vandalized to death). I think there was something about growing trees that signaled that we were serious and cared for the long term and after a few incidents the whole neighborhood really got behind the idea. They were getting watered so much we had to step in to save them from drowning! Now the trees are about 20’ tall and 15’ wide and everyone in the ‘hood enjoys them.
END NOTES

1 http://www.volunteeringinamerica.gov/assets/resources/VolunteeringInAmericaResearch-Highlights.pdf
6 Online documents that can be edited by a group of users, http://en.wikipedia.org/wiki/Wiki
8 http://www.vine.net/
14 http://assets.aarp.org/rgcenter/il/healthy_home.pdf
15 http://online.wsj.com/article/SB123861157569679175.html
16 http://www.ageinplacetech.com/content/intel-ge-alliance-whats-it-mean-aging-place-tech-world
17 http://www.ageinplacetech.com/content/disconnect-between-university-research-and-go-market-product-viability
18 http://www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/chapter01.htm
20 http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892