



Administrative Office of the Courts

Chief Justice Matthew B. Durrant
Utah Supreme Court
Chair, Utah Judicial Council

Daniel J. Becker
State Court Administrator
Raymond H. Wahl
Deputy Court Administrator

October 30, 2013

Dear Guardianship Summit Participant,

Thank you for confirming your attendance at the Utah Guardianship Summit on November 6, 8:30 a.m. - 5:00 p.m., at the Radisson Hotel, 215 W South Temple in Salt Lake City. Complimentary parking is available at the hotel garage located east of the hotel entrance. The hotel is on the Temple Square stop of the TRAX Green and Blue lines.

The summit is sponsored by the Utah Judicial Council and organized by the Working Interdisciplinary Network of Guardianship Stakeholders (WINGS), a multi-disciplinary advisory body, focusing on guardianship issues from different perspectives. Forming such a group was one of the recommendations from the Third National Guardianship Summit held in Salt Lake City in 2011. Utah, New York, Oregon and Texas have been awarded a \$7,000 grant from National Guardianship Network to form WINGS. The WINGS webpage is <http://www.utcourts.gov/howto/family/GC/wings/>.

The initial effort in Utah, approved as part of the grant application, is to invite participants from around the state to a one-day Utah-focused summit to identify issues facing the public, providers, law enforcement, the courts, the bar, etc., and recommend how to respond to those issues. In addition to the plenary sessions, you will participate in a workgroup to evaluate and make recommendations about one of the following topics identified by Utah WINGS:

- Person centered planning and supported decision making
- Medical evidence of incapacity
- Agency cooperation and coordination

The Utah WINGS will prepare the recommendations from the three workgroups for publication and will develop an action plan based on those recommendations.

In the attached materials you will find an agenda for the day, description of each workgroup, information about the speakers, workgroup briefs on the three topics, glossary of terms, list of participants with contact information and an assignment to one of the workgroups. You will receive a folder with the materials at the registration, but we strongly encourage you to familiarize yourself with the workgroup briefs beforehand.

Sincerely,

A handwritten signature in black ink, appearing to read "T. Shea".

Timothy M. Shea
Sr. Staff Attorney

The mission of the Utah judiciary is to provide the people an open, fair, efficient, and independent system for the advancement of justice under the law.

Utah Guardianship Summit
Working Interdisciplinary Network of
Guardianship Stakeholders (WINGS)

November 6, 2013
8:30 a.m. to 5:00 p.m.

Radisson Hotel
215 W South Temple
Salt Lake City, UT 84101

8:30	Registration and Continental Breakfast — Second floor lobby	
9:00	Keynote Address — Parley 1&2 <ul style="list-style-type: none"> • Rev. Tom Goldsmith, First Unitarian Church 	
9:20	Objectives for the Day — Tim Shea, Administrative Office of the Courts	
9:30	Panel: Planning and Making Decisions For Another Adult: Barriers, Challenges and Opportunities <ul style="list-style-type: none"> • Facilitator: Manuel Romero • Panelists: Teri Fuller, Dorothy Henderson, Carleen Kurip, Julie Rigby, Charron Rumble 	
10:45	Break	
11:00	Breakout Sessions <ul style="list-style-type: none"> • (Explore Issues) 	Agency Cooperation — Aspen
		Medical Evidence of Incapacity — Cedar
		Person Centered Planning and Supported Decision Making — Red Butte
12:30	Lunch— Second floor lobby <ul style="list-style-type: none"> • Address by Chris Burbank, Chief of Police, Salt Lake City • Summary of Breakout Sessions: Issues identified 	
1:45	Breakout Sessions <ul style="list-style-type: none"> • (Explore Issues-cont.) • (Resolve Issues) 	Agency Cooperation — Aspen
		Medical Evidence of Incapacity — Cedar
		Person Centered Planning and Supported Decision Making — Red Butte
3:15	Break	
3:30	Reports and Recommendations Parley 1&2	Agency Cooperation
		Medical Evidence of Incapacity
		Person Centered Planning and Supported Decision Making
4:45	Wrap Up — Sally Hurme, Project Advisor, AARP Health Education, Board of National Guardianship Network	
5:00	Adjourn	

Agency Cooperation—Aspen

Government agencies and private organizations necessarily focus their efforts on their core mission. Too much diversity of purpose and the organization will do nothing well. The workgroup will explore the challenges that specialization presents to their clients, how an organization's policies may contribute to those challenges, and how organizations can work collectively to improve services to their clients.

Medical Evidence of Incapacity—Cedar

The Medical Evidence Subgroup will focus on the necessity for medical evidence in guardianship proceedings, and the challenges to presenting thorough, relevant, objective and timely evidence. The goal is to identify three of the greatest problems in obtaining the best evidence about the proposed wards incapacity or lack thereof, and then develop solutions and action steps that will be presented to all attendees of the summit.

Person Centered Planning and Supported Decision Making—Red Butte

Making decisions for another adult is challenging whether the decision maker acts informally or as a court appointed guardian. What are the various ways a decision is made? Who is involved in the decision making process? What information and support does a decision maker need? This workgroup examines best practices for educating the public and stakeholder groups about guardianship, alternatives to guardianship, person centered thinking and planning, and supported decision making.

Reverend Tom Goldsmith

Rev. Tom Goldsmith began his ministry in Salt Lake City in 1987, after serving two churches in the Boston metropolitan area. He has published widely in both cities, including a regular Op Ed column for the Boston Herald, Modern Bride magazine, various articles in both Salt Lake Tribune and Deseret Morning News, many alternative radical feminist and peace periodicals, and he provided a chapter in God and Country: Politics in Utah, Signature Books, 2005.

Rev. Goldsmith has brought his distinct love for jazz to Utah, launching the popular Jazz Vespers program in 1989 and a Folk Vespers series a few years later. He is greatly involved in the interfaith community and has become a regular fixture at peace demonstrations and other human rights events.

In 2000, he married Mary Tull, a consultant with Pathway Associates. Together they have five adult children. Mary plays guitar and sings while Tom attempts to play the bass. They love to hike, travel, and are especially drawn to the beauty and serenity of Torrey, Utah and Bolinas, California.

Chief Chris Burbank

Chief Burbank has been with the Salt Lake City Police Department since 1991. Appointed as Chief of Police in March 2006, he is the 45th Chief of the Department.

Chief Burbank has a B.S. degree in Sociology from the University of Utah and is a graduate of the FBI's National Executive Institute, and serves on the Board of Directors for the National Executive Institute Associates. Chief Burbank serves as the First Vice President of the Major Cities Chiefs Association, an assembly of the 69 largest policing agencies in the U.S. and Canada. He served as the Chair of the Valley Police Alliance during its inception and sits on the Utah Peace Officer Standards and Training Council.

In 2009, Chief Burbank received special recognition from the ACLU of Utah for work in protecting immigrant civil rights and was recognized by the Latino Community Center for his dedication to community policing in building and maintaining a great foundation with the Latino community. In 2010, Chief Burbank was recognized by the Utah Minority Bar Association as their Honoree of the Year for his service to minority communities and dedication to diversity.

He received the Vicki Cottrell Community Hero Award from the Utah National Alliance on Mental Illness for assistance to individuals suffering from mental illness. Chief Burbank was honored for his work on behalf of the women and children by the YWCA Salt Lake City as the 2010 Public Official of the Year.

During the 2002 Salt Lake City Winter Olympic Games Chief Burbank was appointed a Venue Commander, and served as a liaison to the U.S. Secret Service during the Games.

Chief Burbank was chosen by the Salt Lake Tribune as Utahn of the Year for 2011.

Sally Balch Hurme, JD

Sally Hurme is currently a Project Advisor with the AARP Health Education team explaining the workings of the Affordable Care Act and the Health Insurance Marketplaces. While at AARP she has worked on a wide variety of issues including fraud, elder abuse, financial exploitation, guardianship, and advance care planning.

Hurme was honored by the National College of Probate Judges with the Treat Award for excellence in probate law. As chair of the National Guardianship Network she led the planning for the 2011 Third National Guardianship Summit. Hurme is the convener of the 3rd World Congress on Guardianship to be held in Washington, DC in May 2014. She was an advisor to the Uniform Law Commission in the drafting of the uniform guardianship jurisdiction act. Hurme also was a member of the US State Department delegation that drafted the Hague International Convention on the Protection of Adults.

Ms. Hurme is a well-recognized media spokesperson on elder law issues in addition to lecturing in Australia, Italy, Spain, Czech Republic, England, Moldova, Netherlands, and Japan. She has authored 18 law review articles on various elder law issues and taught elder law at George Washington University Law School. She is the author of The ABA Checklist for Family Heirs and is writing a second ABA/AARP Checklist for Survivors.

She received her law degree cum laude from the Washington College of Law at American University and is a long-standing member of the National Academy of Elder Law Attorneys.

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Stanford SOCIAL INNOVATION REVIEW

Collective Impact By John Kania & Mark Kramer

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Collective Impact

LARGE-SCALE SOCIAL CHANGE REQUIRES BROAD CROSS-SECTOR COORDINATION, YET THE SOCIAL SECTOR REMAINS FOCUSED ON THE ISOLATED INTERVENTION OF INDIVIDUAL ORGANIZATIONS.

BY JOHN KANIA & MARK KRAMER

Illustration by Martin Jarric

The scale and complexity of the U.S. public education system has thwarted attempted reforms for decades. Major funders, such as the Annenberg Foundation, Ford Foundation, and Pew Charitable Trusts have abandoned many of their efforts in frustration after acknowledging their lack of progress. Once the global leader—after World War II the United States had the highest high school graduation rate in the world—the country now ranks 18th among the top 24 industrialized nations, with more than 1 million secondary school students dropping out every year. The heroic efforts of countless teachers, administrators, and nonprofits, together with billions of dollars in charitable contributions, may have led to important improvements in individual schools and classrooms, yet system-wide progress has seemed virtually unobtainable.

Against these daunting odds, a remarkable exception seems to be emerging in Cincinnati. Strive, a nonprofit subsidiary of KnowledgeWorks, has brought together local leaders to tackle the student achievement crisis and improve education throughout greater Cincinnati and northern Kentucky. In the four years since the group was launched, Strive partners have improved student success in dozens of key areas across three large public school districts. Despite the recession and budget cuts, 34 of the 53 success indicators that Strive tracks have shown positive trends, including high school graduation rates, fourth-grade reading and math scores, and the number of preschool children prepared for kindergarten.

Why has Strive made progress when so many other efforts have failed? It is because a core group of community leaders decided to abandon their individual agendas in favor of a collective approach to improving student achievement. More than

300 leaders of local organizations agreed to participate, including the heads of influential private and corporate foundations, city government officials, school district representatives, the presidents of eight universities and community colleges, and the executive directors of hundreds of education-related nonprofit and advocacy groups.

These leaders realized that fixing one point on the educational continuum—such as better after-school programs—wouldn't make much difference unless all parts of the continuum improved at the same time. No

single organization, however innovative or powerful, could accomplish this alone. Instead, their ambitious mission became to coordinate improvements at every stage of a young person's life, from "cradle to career."

Strive didn't try to create a new educational program or attempt to convince donors to spend more money. Instead,

through a carefully structured process, Strive focused the entire educational community on a single set of goals, measured in the same way. Participating organizations are grouped into 15 different Student Success Networks (SSNs) by type of activity, such as early childhood education or tutoring. Each SSN has been meeting with coaches and facilitators for two hours every two weeks for the past three years, developing shared performance indicators, discussing their progress, and most important, learning from each other and aligning their efforts to support each other.

Strive, both the organization and the process it helps facilitate, is an example of *collective impact*, the commitment of a group of important actors from different sectors to a common agenda for solving a specific social problem. Collaboration is nothing new. The social sector is filled with examples of partnerships, networks, and other types of joint efforts. But collective impact initiatives are distinctly different. Unlike most



collaborations, collective impact initiatives involve a centralized infrastructure, a dedicated staff, and a structured process that leads to a common agenda, shared measurement, continuous communication, and mutually reinforcing activities among all participants. (See “Types of Collaborations” on page 39.)

Although rare, other successful examples of collective impact are addressing social issues that, like education, require many different players to change their behavior in order to solve a complex problem. In 1993, Marjorie Mayfield Jackson helped found the Elizabeth River Project with a mission of cleaning up the Elizabeth River in southeastern Virginia, which for decades had been a dumping ground for industrial waste. They engaged more than 100 stakeholders, including the city governments of Chesapeake, Norfolk, Portsmouth, and Virginia Beach, Va., the Virginia Department of Environmental Quality, the U.S. Environmental Protection Agency (EPA), the U.S. Navy, and dozens of local businesses, schools, community groups, environmental organizations, and universities, in developing an 18-point plan to restore the watershed. Fifteen years later, more than 1,000 acres of watershed land have been conserved or restored, pollution has been reduced by more than 215 million pounds, concentrations of the most severe carcinogen have been cut sixfold, and water quality has significantly improved. Much remains to be done before the river is fully restored, but already 27 species of fish and oysters are thriving in the restored wetlands, and bald eagles have returned to nest on the shores.

Or consider Shape up Somerville, a citywide effort to reduce and prevent childhood obesity in elementary school children in Somerville, Mass. Led by Christina Economos, an associate professor at Tufts University’s Gerald J. and Dorothy R. Friedman School of Nutrition Science and Policy, and funded by the Centers for Disease Control and Prevention, the Robert Wood Johnson Foundation, Blue Cross Blue Shield of Massachusetts, and United Way of Massachusetts Bay and Merrimack Valley, the program engaged government officials, educators, businesses, nonprofits, and citizens in collectively defining wellness and weight gain prevention practices. Schools agreed to offer healthier foods, teach nutrition, and promote physical activity. Local restaurants received a certification if they served low-fat, high nutritional food. The city organized a farmers’ market and provided healthy lifestyle incentives such as reduced-price gym memberships for city employees. Even sidewalks were modified and crosswalks repainted to encourage more children to walk to school. The result was a statistically significant decrease in body mass index among the community’s young children between 2002 and 2005.

Even companies are beginning to explore collective impact to tackle social problems. Mars, a manufacturer of chocolate brands such as M&M’s, Snickers, and Dove, is working with NGOs, local governments, and even direct competitors to improve the lives of more than 500,000 impoverished cocoa farmers in Cote d’Ivoire, where Mars sources a large portion of its cocoa. Research suggests

that better farming practices and improved plant stocks could triple the yield per hectare, dramatically increasing farmer incomes and improving the sustainability of Mars’s supply chain. To accomplish this, Mars must enlist the coordinated efforts of multiple organizations: the Cote d’Ivoire government needs to provide more agricultural extension workers, the World Bank needs to finance new roads, and bilateral donors need to support NGOs in improving health care, nutrition, and education in cocoa growing communities. And Mars must find ways to work with its direct competitors on pre-competitive issues to reach farmers outside its supply chain.

These varied examples all have a common theme: that large-scale social change comes from better cross-sector coordination rather than from the isolated intervention of individual organizations. Evidence of the effectiveness of this approach is still limited, but these examples suggest that substantially greater progress could be made in alleviating many of our most serious and complex social problems if nonprofits, governments, businesses, and the public were brought together around a common agenda to create collective impact. It doesn’t happen often, not because it is impossible, but because it is so rarely attempted. Funders and nonprofits alike overlook the potential for collective impact because they are used to focusing on independent action as the primary vehicle for social change.

ISOLATED IMPACT

Most funders, faced with the task of choosing a few grantees from many applicants, try to ascertain which organizations make the greatest contribution toward solving a social problem. Grantees, in turn, compete to be chosen by emphasizing how their individual activities produce the greatest effect. Each organization is judged on its own potential to achieve impact, independent of the numerous other organizations that may also influence the issue. And when a grantee is asked to evaluate the impact of its work, every attempt is made to isolate that grantee’s individual influence from all other variables.

In short, the nonprofit sector most frequently operates using an approach that we call *isolated impact*. It is an approach oriented toward finding and funding a solution embodied within a single organization, combined with the hope that the most effective organizations will grow or replicate to extend their impact more widely. Funders search for more effective interventions as if there were a cure for failing schools that only needs to be discovered, in the way that medical cures are discovered in laboratories. As a result of this process, nearly 1.4 million nonprofits try to invent independent solutions to major social problems, often working at odds with each other and exponentially increasing the perceived resources required to make meaningful progress. Recent trends have only reinforced this perspective. The growing interest in venture philanthropy and social entrepreneurship, for example, has greatly benefited the social sector by identifying and accelerating the growth of many high-performing nonprofits, yet it has also accentuated an emphasis on scaling up a few select organizations as the key to social progress.

Despite the dominance of this approach, there is scant evidence that isolated initiatives are the best way to solve many social problems in today’s complex and interdependent world. No single organization is responsible for any major social problem, nor can any single

JOHN KANIA is a managing director at FSG, where he oversees the firm’s consulting practice. Before joining FSG, he was a consultant at Mercer Management Consulting and Corporate Decisions Inc. This is Kania’s third article for the *Stanford Social Innovation Review*.

MARK KRAMER is the co-founder and a managing director of FSG. He is also the co-founder and the initial board chair of the Center for Effective Philanthropy, and a senior fellow at Harvard University’s John F. Kennedy School of Government. This is Kramer’s fifth article for the *Stanford Social Innovation Review*.

TYPES OF COLLABORATIONS

Organizations have attempted to solve social problems by collaboration for decades without producing many results. The vast majority of these efforts lack the elements of success that enable collective impact initiatives to achieve a sustained alignment of efforts.

Funder Collaboratives are groups of funders interested in supporting the same issue who pool their resources. Generally, participants do not adopt an overarching evidence-based plan of action or a shared measurement system, nor do they engage in differentiated activities beyond check writing or engage stakeholders from other sectors.

Public-Private Partnerships are partnerships formed between government and private sector organizations to deliver specific services or benefits. They are often targeted narrowly, such as developing a particular drug to fight a single disease, and usually don't engage the full set of stakeholders that affect the issue, such as the potential drug's distribution system.

Multi-Stakeholder Initiatives are voluntary activities by stakeholders from different sectors around a common theme. Typically, these initiatives lack any shared measurement of impact and the supporting infrastructure to forge any true alignment of efforts or accountability for results.

Social Sector Networks are groups of individuals or organizations fluidly connected through purposeful relationships, whether formal or informal. Collaboration is generally ad hoc, and most often the emphasis is placed on information sharing and targeted short-term actions, rather than a sustained and structured initiative.

Collective Impact Initiatives are long-term commitments by a group of important actors from different sectors to a common agenda for solving a specific social problem. Their actions are supported by a shared measurement system, mutually reinforcing activities, and ongoing communication, and are staffed by an independent backbone organization.

organization cure it. In the field of education, even the most highly respected nonprofits—such as the Harlem Children's Zone, Teach for America, and the Knowledge Is Power Program (KIPP)—have taken decades to reach tens of thousands of children, a remarkable achievement that deserves praise, but one that is three orders of magnitude short of the tens of millions of U.S. children that need help.

The problem with relying on the isolated impact of individual organizations is further compounded by the isolation of the nonprofit sector. Social problems arise from the interplay of governmental and commercial activities, not only from the behavior of social sector organizations. As a result, complex problems can be solved only by cross-sector coalitions that engage those outside the nonprofit sector.

We don't want to imply that all social problems require collective impact. In fact, some problems are best solved by individual organizations. In "Leading Boldly," an article we wrote with Ron Heifetz for the winter 2004 issue of the *Stanford Social Innovation Review*, we described the difference between *technical problems* and *adaptive problems*. Some social problems are technical in that the problem is well defined, the answer is known in advance, and one or a few organizations have the ability to implement the solution. Examples include funding college scholarships, building a hospital, or installing inventory controls in a food bank. Adaptive problems, by contrast, are complex, the answer is not known, and even if it were, no single entity has the resources or authority to bring about the necessary change. Reforming public education, restoring wetland environments, and improving community health are all adaptive problems. In these cases, reaching an effective solution requires learning by the stakeholders involved in the problem, who must then change their own behavior in order to create a solution.

vision for change, one that includes a common understanding of the problem and a joint approach to solving it through agreed upon actions. Take a close look at any group of funders and nonprofits that believe they are working on the same social issue, and you quickly find that it is often not the same issue at all. Each organization often has a slightly different definition of the problem and the ultimate goal. These differences are easily ignored when organizations work independently on isolated initiatives, yet these differences splinter the efforts and undermine the impact of the field as a whole. Collective impact requires that these differences be discussed and resolved. Every participant need not agree with every other participant on all dimensions of the problem. In fact, disagreements continue to divide participants in all of our examples of collective impact. All participants must agree, however, on the primary goals for the collective impact initiative as a whole. The Elizabeth River Project, for example, had to find common ground among the different objectives of corporations, governments, community groups, and local citizens in order to establish workable cross-sector initiatives.

Funders can play an important role in getting organizations to act in concert. In the case of Strive, rather than fueling hundreds of strategies and nonprofits, many funders have aligned to support Strive's central goals. The Greater Cincinnati Foundation realigned its education goals to be more compatible with Strive, adopting Strive's annual report card as the foundation's own measures for progress in education. Every time an organization applied to Duke Energy for a grant, Duke asked, "Are you part of the [Strive] network?" And when a new funder, the Carol Ann and Ralph V. Haile Jr./U.S. Bank Foundation, expressed interest in education, they were encouraged by virtually every major education leader in Cincinnati to join Strive if they wanted to have an impact in local education.¹

Shifting from isolated impact to collective impact is not merely a matter of encouraging more collaboration or public-private partnerships. It requires a systemic approach to social impact that focuses on the relationships between organizations and the progress toward shared objectives. And it requires the creation of a new set of nonprofit management organizations that have the skills and resources to assemble and coordinate the specific elements necessary for collective action to succeed.

THE FIVE CONDITIONS OF COLLECTIVE SUCCESS

Our research shows that successful collective impact initiatives typically have five conditions that together produce true alignment and lead to powerful results: a common agenda, shared measurement systems, mutually reinforcing activities, continuous communication, and backbone support organizations.

Common Agenda | Collective impact requires all participants to have a shared

Shared Measurement Systems | Developing a shared measurement system is essential to collective impact. Agreement on a common agenda is illusory without agreement on the ways success will be measured and reported. Collecting data and measuring results consistently on a short list of indicators at the community level and across all participating organizations not only ensures that all efforts remain aligned, it also enables the participants to hold each other accountable and learn from each other's successes and failures.

It may seem impossible to evaluate hundreds of different organizations on the same set of measures. Yet recent advances in Web-based technologies have enabled common systems for reporting performance and measuring outcomes. These systems increase efficiency and reduce cost. They can also improve the quality and credibility of the data collected, increase effectiveness by enabling grantees to learn from each other's performance, and document the progress of the field as a whole.²

All of the preschool programs in Strive, for example, have agreed to measure their results on the same criteria and use only evidence-based decision making. Each type of activity requires a different set of measures, but all organizations engaged in the same type of activity report on the same measures. Looking at results across multiple organizations enables the participants to spot patterns, find solutions, and implement them rapidly. The preschool programs discovered that children regress during the summer break before kindergarten. By launching an innovative "summer bridge" session, a technique more often used in middle school, and implementing it simultaneously in all preschool programs, they increased the average kindergarten readiness scores throughout the region by an average of 10 percent in a single year.³

Mutually Reinforcing Activities | Collective impact initiatives depend on a diverse group of stakeholders working together, not by requiring that all participants do the same thing, but by encouraging each participant to undertake the specific set of activities at which it excels in a way that supports and is coordinated with the actions of others.

The power of collective action comes not from the sheer number of participants or the uniformity of their efforts, but from the coordination of their differentiated activities through a mutually reinforcing plan of action. Each stakeholder's efforts must fit into an overarching plan if their combined efforts are to succeed. The multiple causes of social problems, and the components of their solutions, are interdependent. They cannot be addressed by uncoordinated actions among isolated organizations.

All participants in the Elizabeth River Project, for example, agreed on the 18-point watershed restoration plan, but each is playing a different role based on its particular capabilities. One group of organizations works on creating grassroots support and engagement among citizens, a second provides peer review and recruitment for industrial participants who voluntarily reduce pollution, and a third coordinates and reviews scientific research.

The 15 SSNs in Strive each undertake different types of activities at different stages of the educational continuum. Strive does not prescribe what practices each of the 300 participating organizations should pursue. Each organization and network is free to chart its own course consistent with the common agenda, and informed by the shared measurement of results.

Continuous Communication | Developing trust among nonprofits, corporations, and government agencies is a monumental challenge. Participants need several years of regular meetings to build up enough experience with each other to recognize and appreciate the common motivation behind their different efforts. They need time to see that their own interests will be treated fairly, and that decisions will be made on the basis of objective evidence and the best possible solution to the problem, not to favor the priorities of one organization over another.

Even the process of creating a common vocabulary takes time, and it is an essential prerequisite to developing shared measurement systems. All the collective impact initiatives we have studied held monthly or even biweekly in-person meetings among the organizations' CEO-level leaders. Skipping meetings or sending lower-level delegates was not acceptable. Most of the meetings were supported by external facilitators and followed a structured agenda.

The Strive networks, for example, have been meeting regularly for more than three years. Communication happens between meetings too: Strive uses Web-based tools, such as Google Groups, to keep communication flowing among and within the networks. At first, many of the leaders showed up because they hoped that their participation would bring their organizations additional funding, but they soon learned that was not the meetings' purpose. What they discovered instead were the rewards of learning and solving problems together with others who shared their same deep knowledge and passion about the issue.

Backbone Support Organizations | Creating and managing collective impact requires a separate organization and staff with a very specific set of skills to serve as the backbone for the entire initiative. Coordination takes time, and none of the participating organizations has any to spare. The expectation that collaboration can occur without a supporting infrastructure is one of the most frequent reasons why it fails.

The backbone organization requires a dedicated staff separate from the participating organizations who can plan, manage, and support the initiative through ongoing facilitation, technology and communications support, data collection and reporting, and handling the myriad logistical and administrative details needed for the initiative to function smoothly. Strive has simplified the initial staffing requirements for a backbone organization to three roles: project manager, data manager, and facilitator.

Collective impact also requires a highly structured process that leads to effective decision making. In the case of Strive, staff worked with General Electric (GE) to adapt for the social sector the Six Sigma process that GE uses for its own continuous quality improvement. The Strive Six Sigma process includes training, tools, and resources that each SSN uses to define its common agenda, shared measures, and plan of action, supported by Strive facilitators to guide the process.

In the best of circumstances, these backbone organizations embody the principles of adaptive leadership: the ability to focus people's attention and create a sense of urgency, the skill to apply pressure to stakeholders without overwhelming them, the competence to frame issues in a way that presents opportunities as well as difficulties, and the strength to mediate conflict among stakeholders.

FUNDING COLLECTIVE IMPACT

Creating a successful collective impact initiative requires a significant financial investment: the time participating organizations must dedicate to the work, the development and monitoring of shared measurement systems, and the staff of the backbone organization needed to lead and support the initiative's ongoing work.

As successful as Strive has been, it has struggled to raise money, confronting funders' reluctance to pay for infrastructure and preference for short-term solutions. Collective impact requires instead that funders support a long-term process of social change without identifying any particular solution in advance. They must be willing to let grantees steer the work and have the patience to stay with an initiative for years, recognizing that social change can come from the gradual improvement of an entire system over time, not just from a single breakthrough by an individual organization.

This requires a fundamental change in how funders see their role, from funding organizations to leading a long-term process of social change. It is no longer enough to fund an innovative solution created by a single nonprofit or to build that organization's capacity. Instead, funders must help create and sustain the collective processes, measurement reporting systems, and community leadership that enable cross-sector coalitions to arise and thrive.

This is a shift that we foreshadowed in both "Leading Boldly" and our more recent article, "Catalytic Philanthropy," in the fall 2009 issue of the *Stanford Social Innovation Review*. In the former, we suggested that the most powerful role for funders to play in addressing adaptive problems is to focus attention on the issue and help to create a process that mobilizes the organizations involved to find a solution themselves. In "Catalytic Philanthropy," we wrote: "Mobilizing and coordinating stakeholders is far messier and slower work than funding a compelling grant request from a single organization. Systemic change, however, ultimately depends on a sustained campaign to increase the capacity and coordination of an entire field." We recommended that funders who want to create large-scale change follow four practices: take responsibility for assembling the elements of a solution; create a movement for change; include solutions from outside the nonprofit sector; and use actionable knowledge to influence behavior and improve performance.

These same four principles are embodied in collective impact initiatives. The organizers of Strive abandoned the conventional approach of funding specific programs at education nonprofits and took responsibility for advancing education reform themselves. They built a movement, engaging hundreds of organizations in a drive toward shared goals. They used tools outside the nonprofit sector, adapting GE's Six Sigma planning process for the social sector. And through the community report card and the biweekly meetings of the SSNs they created actionable knowledge that motivated the community and improved performance among the participants.

Funding collective impact initiatives costs money, but it can be a highly leveraged investment. A backbone organization with a modest annual budget can support a collective impact initiative of several hundred organizations, magnifying the impact of millions or even billions of dollars in existing funding. Strive, for example, has a \$1.5 million annual budget but is coordinating the efforts and

increasing the effectiveness of organizations with combined budgets of \$7 billion. The social sector, however, has not yet changed its funding practices to enable the shift to collective impact. Until funders are willing to embrace this new approach and invest sufficient resources in the necessary facilitation, coordination, and measurement that enable organizations to work in concert, the requisite infrastructure will not evolve.

FUTURE SHOCK

What might social change look like if funders, nonprofits, government officials, civic leaders, and business executives embraced collective impact? Recent events at Strive provide an exciting indication of what might be possible.

Strive has begun to codify what it has learned so that other communities can achieve collective impact more rapidly. The organization is working with nine other communities to establish similar cradle to career initiatives.⁴ Importantly, although Strive is broadening its impact to a national level, the organization is not scaling up its own operations by opening branches in other cities. Instead, Strive is promulgating a flexible process for change, offering each community a set of tools for collective impact, drawn from Strive's experience but adaptable to the community's own needs and resources. As a result, the new communities take true ownership of their own collective impact initiatives, but they don't need to start the process from scratch. Activities such as developing a collective educational reform mission and vision or creating specific community-level educational indicators are expedited through the use of Strive materials and assistance from Strive staff. Processes that took Strive several years to develop are being adapted and modified by other communities in significantly less time.

These nine communities plus Cincinnati have formed a community of practice in which representatives from each effort connect regularly to share what they are learning. Because of the number and diversity of the communities, Strive and its partners can quickly determine what processes are universal and which require adaptation to a local context. As learning accumulates, Strive staff will incorporate new findings into an Internet-based knowledge portal that will be available to any community wishing to create a collective impact initiative based on Strive's model.

This exciting evolution of the Strive collective impact initiative is far removed from the isolated impact approach that now dominates the social sector and that inhibits any major effort at comprehensive, large-scale change. If successful, it presages the spread of a new approach that will enable us to solve today's most serious social problems with the resources we already have at our disposal. It would be a shock to the system. But it's a form of shock therapy that's badly needed. ■

Notes

- 1 Interview with Kathy Merchant, CEO of the Greater Cincinnati Foundation, April 10, 2010.
- 2 See Mark Kramer, Marcie Parkhurst, and Lalitha Vaidyanathan, *Breakthroughs in Shared Measurement and Social Impact*, PSG Social Impact Advisors, 2009.
- 3 "Successful Starts," United Way of Greater Cincinnati, second edition, fall 2009.
- 4 Indianapolis, Houston, Richmond, Va., and Hayward, Calif., are the first four communities to implement Strive's process for educational reform. Portland, Ore., Fresno, Calif., Mesa, Ariz., Albuquerque, and Memphis are just beginning their efforts.

Medical Evidence of Incapacity

Workgroup Brief for Utah Guardianship Summit - WINGS November 6, 2013

This paper will provide attendees of the WINGS Summit background for the Medical Evidence Workgroup sessions. After a presentation by the three panelists of this workgroup, the participants will collectively identify the four most important issues facing health care professionals, attorneys and judges in the presentation of relevant, high quality medical and psychological evidence necessary in guardianship proceedings. We will then brainstorm potential solutions to the problems and outline action steps. At the end of the day all three workgroups will present their list of issues, solutions and action steps.

There is a presumption among lawyers and judges that the medical profession can give definitive information on whether an individual is incapacitated as defined by law. Medical professionals look to attorneys to define for them what must be proven in court to find that an individual is incapacitated. This is a more complicated relationship than one might assume. The medical professionals are not necessarily clear about the type of information that is most useful to the judge. They often do not know when this information is presented, what form it should take and who submits it. Attorneys representing the parties in guardianship proceedings often do not know which type of health care professional is the best source of medical information addressing the incapacity of the respondent and how the health care professional will be reimbursed for the cost of preparing the necessary information.

At the beginning of our workgroup session the panelists will discuss the following issues: (1) what medical evidence is required to prove incapacity; (2) in what format should the medical evidence be provided by the medical or social work professionals to the court, who requests it and how it is presented to the court; (3) what health professionals are the best source of information for the medical evidence of incapacity; (4) how the health evaluation should be paid for. While the workgroup has identified these issues as most critical, participants can raise other issues and include them in the final report to all participants of the Summit.

SCENARIOS

The panelists will use four scenarios to lay out these issues. They are as follows:

Two daughters sought the advice of an attorney to obtain guardianship and conservatorship for their mother Grace. Over the past 2 years they had noticed their 90-year old mother was becoming forgetful. She had remarried 5 years ago after her first husband died. Her daughters had never been completely reconciled with her decision to remarry. Grace is now living with her husband and his son in Grace's home. She also has about \$500,000 in readily available assets. A few days after a recent hip surgery while she was still taking pain medication, one of the daughters took Grace to Grace's primary care physician,

an internist, who had treated her for the last eight years. The daughter requested a letter stating that she is incompetent. He briefly talked to Grace and provided the letter. The letter gave no details about how she functions or how her various diagnoses affect her ability to be independent. He had not previously noted in any of his records any cognitive problems. He did not know about the various supports Grace had in her life, such as family, friends and members of her church. The primary care physician told the daughters that he did not have time to write up a comprehensive summary of Grace's condition. Grace has had no other treating physician for ten years. Grace and her husband stated that a daughter had previously "duped them" out of a property Grace had owned, but they had not pursued this legally.

Jim is twenty-four year old and has been diagnosed with a mild intellectual disability. He was in special education services until he turned twenty-two. He now lives with his parents. He was born with a heart condition that has been monitored all of his life, but has required no serious medical interventions. His parents fear that the condition could become worse at any time and require surgery. Jim also has physical limitations that have required physical and occupational therapy for much of his life. He has been evaluated for state services related to his intellectual disabilities, but is on a waiting list to receive those services. Jim's parents met with an attorney to talk about guardianship.

Cheryl is thirty two years old. She was a world class snowboarder when she crashed during a race, suffering significant brain injuries as well as a lower back injury that limits her ability to walk without the use of crutches. She receives medical treatment for her back injury from a rehabilitation physician and physical therapists. She also is treated for her brain injury by a neuropsychologist and social worker. Due to her brain injury she has low impulse control and limited executive functioning.

Ralph has a serious bipolar disorder. The impact of the disease is cyclical. A significant amount of time he is fully functional and can make his own decisions. In his manic phases he hears voices, acts very erratically and has been arrested four times for shoplifting and simple assault. He often refuses to take his medication. When he does he will be in a persistent manic phase. He receives mental health treatment from the local mental health agency. His relationship with his family is strained, but he has a close friend from his childhood that still offers him a great deal of support.

MEDICAL EVIDENCE

A judge cannot find that an individual is incapacitated and in need of a guardian without some medical evidence of the individual's ability to make decisions that will meet their basic needs and provide them safety. In any case the judge must first find that the individual has a physical or medical impairment. That can only be demonstrated through medical evidence. The judge must then find that there is a link between the mental or physical impairment and the limitations the person has that

impairs their decisions to such an extent that they need a guardian. The need for a guardian must be proven by clear and convincing evidence. Given this standard this link reasonably must be demonstrated by medical evidence, either through documents or testimony of a health care professional. Anything else is too speculative.

Evidence of Incapacity

A guardian can be appointed based upon the “incapacity” of the respondent. Under law incapacity is

measured by functional limitations and means a judicial determination after proof by clear and convincing evidence that an adult's ability to do the following is impaired to the extent that the individual lacks the ability, even with appropriate technological assistance, to meet the essential requirements for financial protection or physical health, safety, or self-care: (a) receive and evaluate information; (b) make and communicate decisions; or (c) provide for necessities such as food, shelter, clothing, health care, or safety. Utah Code Annotated § 75-1-201(22).

The key here is that the focus is on the respondent’s functional limitations. Those limitations must be a consequence of a medical condition. Medical evidence of incapacity must specifically identify their diagnosis(es) or condition(s), the types of functional limitations that are a consequence of that diagnosis or condition, and how those limitations relate to the individual’s level of incapacity.

Form of the Necessary Medical Evidence of Incapacity

There is nothing specific in that law about the type of information a health care professional should provide to the court. The information from the professional should address the elements of the definition of incapacity as directly as possible. The best information of the respondent’s incapacity will come from a contemporaneous report or evaluation written by the treating health care professional. Such evaluations will need to be written by the health care professional at the time the guardianship is requested. However, in a minority of cases such evaluations may have been written previously in the normal course of treatment. This is more likely for people with intellectual disabilities and traumatic brain injuries. Treating mental health professionals may be assessing the ability of their patient to consent to medications. In these circumstances the report should be relatively recent, unless the alleged incapacitated person’s condition is basically static. Also, some test results or evaluations may be adequate even though they older. For instance, an I.Q. test administered to someone with an intellectual disability may be informative even if it is ten or more years old. I.Q. scores rarely change significantly over the years. A good test will also identify limitations in brain functioning that also do not change much. These functions can directly point to functional limitations that impact the individual’s ability to make minimally adequate decisions to meet their basic needs. As an example, a report on an I.Q. test may identify subset results that indicate a lack of executive functioning. This will negatively impact the individual’s ability to generalize

what they learn from various experiences, and to think in terms of long term risks and benefits. That individual's decisions will generally be made based only on immediate circumstances.

Health Professionals that Provide Evaluation

There is no statutory guidance or procedural rule to guide the judge on identifying the appropriate type of health care professional that should conduct these examinations. The law only states "physician." In some cases a physician may not be the best source of information. The medical/psychological information will preferably come from the treating health care professional who is addressing the conditions that are contributing to the decision-making limitations. They will know the respondent best regarding his or her ability to make minimally adequate decisions directed towards meeting their basic needs and safety. What health care professional this will depend on the medical condition involved. When the diagnosed condition is Dementia or Alzheimer's, the best source of information would be the physician treating the condition, and possibly a neuropsychologist or social worker working with the physician. In other words, it should not be the individual's urologist. In the case of an individual with severe and persistent mental illness the best source of information would be the treating psychiatrist, psychologist or social worker. Which of those three would be best might depend upon who is the most involved with the individual's ongoing treatment. When the individual has an intellectual disability the best source of information would be a psychologist or social worker. A psychiatrist likely won't be involved with the individual, but if one is, they could also be a good source of information. Finally, if the individual has a traumatic brain injury, health care professionals to turn to would include a rehabilitation physician, neuropsychologist, clinical psychologist or social worker.

Court Process to Determine Incapacity

Guardianships and conservatorships are generally considered non-adversarial. All of the parties are usually in agreement about the relevant facts of the case, which is whether the alleged incapacitated person needs protection or can make decisions about their basic needs. A case will be considered contested if there is a dispute about the relevant facts. Proof of incapacity, and in some cases, who should be the guardian, will then be the major issues.

The first step in a guardianship case is to determine whether the petition is contested or uncontested. This will take place approximately one month after the petition for guardianship is filed. The depth of medical evidence needed depends upon whether a guardianship is contested or uncontested. As things stand now, a minimal amount of evidence demonstrating incapacity must be in the petitioner's hand at the initial court hearing when the parties find out whether the matter is contested or not. In uncontested proceedings medical evidence as simple as an informal letter from a physician or psychologist stating that they have examined the protected person and is of the opinion that the person needs assistance or protection is sufficient. The clear and convincing evidence standard still applies here, but, as a practical matter, a judge

will accept less evidence. Our challenge is to provide the judge in an uncontested case more of the evidence the judge expects in a contested case. If the case is contested by the alleged incapacitated person or another interested person (family member) then medical evidence and incapacity becomes a major issue. In that case much more evidence, the health care professional's report, along with supporting documents and testimony at trial will likely be necessary.

Often times the type of medical evidence discussed above will not be available. Where there is no good source of information, the court can order an examination of the alleged incapacitated person. The physician ordered to conduct the evaluation will submit a report to the court. Utah Code Annotated § 75-5-303(4); U.C.A. § 75-5-407(4). While the statute says "physician" the judge has the ability to appoint a different type of health care professional that is more appropriate.

Ideally, the petitioners in the guardianship proceeding have the medical evidence of the respondent's incapacity in hand at the time of filing the petition. The petitioners and their legal counsel should evaluate what evidence will be needed and attempt to get the evidence before filing the petition. Some of that evidence can then be submitted as part of the initial petition. If that is not possible, due to a treating health care professional's unwillingness to become involved in the proceedings, or the lack of a treating health care professional or recent history of treatment, the attorney should make arrangements for a medical examination and obtain a court appointment of the health care professional at the same time the petition is filed.

In a contested case, the medical evaluation will need to be more detailed, setting forth the health care professional's testing process and observations which lead their final conclusion that the alleged incapacitated person either does or does not lack the functional ability to take in and process information, make reasonable decisions based on that processing, and is or is not able to provide for the necessities of life, health care or safety because of their ability to take in and process information. The health care professional should be prepared to be called as a witness at an evidentiary hearing to testify about their qualifications to do the evaluation and the process followed to reach their conclusion.

Cost of Providing Health Evaluation

One barrier to putting together sufficient medical evidence is the cost of producing that evidence. Remember, in the majority of cases there are no existing evaluations of the individual's capacity to make minimally adequate decisions. Private insurance companies, Medicare and Medicaid typically do not pay for evaluations of capacity for the purposes of a guardianship proceeding. They will only pay for those necessary for medical treatment. The challenge to the health care provider is to "creatively" request reimbursement under a particular reimbursement code. This will be discussed by the panelists at the session.

Person Centered Planning and Supported Decision Making

Workgroup Brief for Utah Guardianship Summit - WINGS November 6, 2013

Making decisions for an adult with diminished capacity is challenging whether the decision maker acts informally or as a court appointed guardian. What are the various ways a decision is made? Who is involved in the decision making process? What information and support are needed by a decision maker as well as by the person in need of help with decision making? What do service providers who engage with the decision maker need to know? What are the best ways to deliver this information and support?

This brief provides attendees of the WINGS Summit with some background information concerning the Person Centered Planning and Supported Decision Making workgroup sessions. Our workgroup's goal is to emerge from the statewide Summit with an action plan to implement education tools and methods of delivery. After a morning plenary session presentation by the five panelists of this workgroup, the workgroup participants will identify no more than four of the most important issues facing the public and stakeholder groups on surrogate decision making, person centered thinking and planning, and supported decision making. We will then brainstorm potential best practices for educating the public and stakeholders about these issues, and determine specific action steps. At the end of the day, all three Summit workgroups will present their action steps at a plenary session.

Guardianship in Utah: Brief Overview of Current Situation

Anyone 18 or older has the right to make decisions based on his or her values and beliefs, even if others disagree with those decisions. Every day we make decisions for ourselves and for the people who depend on us. Decision making can be burdensome, even stressful at times, but few of us would willingly give up the right to make our own decisions. An adult who loses the capacity to make decisions, or a person born with intellectual disabilities who has never had decision making capabilities but who is now an adult, may need special protection.

Utah law, like the U.S. legal system in general, has created mechanisms that authorize others to make decisions for persons with intellectual and cognitive disabilities. The most powerful of these surrogate decision making mechanisms is a guardianship proceeding in which a court appoints a third party to make decisions for a person who is determined to be incapacitated.

In any given year, there are about 1,500 new adult guardianship and conservatorship petitions filed in Utah. At any given time, there are about 12,000 active cases. These numbers are projected to grow.

A guardian is a person or institution appointed by a court to make decisions about the personal well-being — residence, health care, nutrition, education, personal care, etc. — of an incapacitated adult, who is called a "protected person." A conservator is a person or institution appointed by the court to make decisions about a protected person's estate.

Before a guardian or conservator is appointed, the alleged incapacitated person is also referred to as the "respondent." Once the guardian or conservator is appointed, the incapacitated person is referred to as the "protected person."

The protected person's estate includes all of his or her property, business and personal. Some examples are income (such as wages, an annuity, a pension, and Social Security or other government benefits), real property (buildings and land), and personal property (furniture, cash, bank accounts, certificates of deposit, stocks, bonds, motor vehicles, and valuables such as jewelry, tools, furs and art). A conservator must use reasonable care, skill and caution to manage and invest the estate to meet the protected person's needs over his or her expected life.

Under appropriate facts, the court might appoint a guardian or a conservator or both. The guardian and the conservator might be two different people, or they might be the same person. If there is no conservator, the guardian has some of the conservator's responsibilities.

If the protected person needs help in some but not all areas of decision making, the court will order a limited guardianship. A limited guardianship is preferred under Utah law, and the court will grant a full guardianship only if no alternative exists. A limited guardian has only those powers listed in the court order. The court can also limit the authority of a conservator. Even though Utah law prefers a limited guardianship order, the reality is that the vast majority of guardianships are plenary, giving the guardian full decision making authority over the protected person.

Being a guardian or conservator is a demanding role. A guardian and conservator are responsible for decisions for another person, and they must always act with the utmost honesty, loyalty and fidelity toward that person. A guardian and conservator must always act in good faith. A guardian and conservator also owe duties to the court: They must report annually to the court; they must advise the court when either they or the protected person changes residence; and they must follow all court orders.

A guardian and conservator help the protected person make decisions or, if necessary, make decisions for the protected person. But the guardian and conservator cannot simply do what they want. The guardian and conservator should make the same decision that the protected person would make, unless that decision will cause harm. It is important that the guardian and conservator become and remain personally involved with the protected person to know of his or her preferences, values, capabilities, limitations, needs, opportunities, and physical and mental health.

A guardianship and conservatorship removes the fundamental right of the protected person to make his or her own decisions. Asking the court to appoint a guardian or conservator should be a last resort, after all other, less intrusive means have been examined first.

The 2009 Report by the Utah State Courts Ad Hoc Committee on Probate Law and Procedure made, in part, the following observations concerning guardianship:

“Appointing a guardian or a conservator is one the most significant interventions by a court into a person’s life. Like a prison sentence or commitment to a mental health facility, the appointment takes from that person the freedom to decide for oneself many, and often times all, of the large and small issues we face every day. Appointing a guardian or conservator legally changes an adult into a child once more, and, as with a child, someone else decides those questions. Indeed, under current Utah law, “Absent a specific limitation, the guardian has the same powers, rights, and duties respecting the ward that a parent has respecting the parent’s unemancipated minor child...” Utah Code Section 75-5-312(2).

The guardian is usually granted plenary authority over the respondent with little or no exploration of the respondent’s capabilities and in the face of laws that prefer limited authority.

Most petitions are filed in good faith to appoint a person of goodwill who will serve in the best interests of the protected person, but we rely primarily on good faith and goodwill to achieve that result. Good intentions and lack of oversight have, over time, led to summary proceedings [that is, court proceedings in which no objections are heard and that do not include evidentiary hearings] that presume to protect the respondent from others and from self, but that offer little real protection from the process itself or from those we put in charge of the respondent’s life. And even one case in which the fiduciary takes advantage of the person s/he is supposed to take care of is one too many. Summary proceedings and trust in the capability and goodwill of guardians and conservators are easy, but they deny many respondents the level of independence they may be capable of.

To be sure, there are cases in which the respondent is so clearly incapacitated that substantial medical evidence would be costly and without purpose. There are cases in which the respondent is so fully incapacitated that plenary control over that person is the most appropriate arrangement. But not in all cases. Many cases present nuances that need to be explored and capacities that need to be protected.”

There is very little guidance under the law and in practice as to how a guardian should make decisions for the protected person. The list of resources at the end of this brief indicate several of the more well-known resources in Utah, but guardians, and other surrogate decision makers, need help in making decisions

and in including others in the decision making process. In addition, many service providers (including medical care providers, long-term care facility staff and administration, social services providers, and law enforcement, among others) often require a decision maker to be a court appointed guardian in order to have the ability to authorize services for the person with intellectual and cognitive disabilities, but those service providers do not understand well how decisions are and/or should be made.

Overview of Person Centered Planning and Supported Decision Making

Recent national and international efforts examine whether surrogate decision making should be encouraged outside of a traditional court ordered guardianship. Such efforts offer person centered planning and supported decision making as possible models. These efforts are due in part to the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Guardianship is often criticized for a variety of reasons, including that it is overly intrusive, not well monitored, anti-therapeutic, and violates the civil rights of the protected person. A. Frank Johns, a national expert on guardianship, notes:

“While countless American studies have found that guardianship protects those adults amongst us who are helpless and vulnerable, they have also uncovered evils in guardianship: removing all individual rights; denying access, connection, and voice to those lost in guardianship’s gulag; and still continuing a process rooted in systemic perversities. Recent reexaminations of monitoring and public guardians acknowledge that guardianship still limits the autonomy, individuality, self-esteem, and self-determinations of AIPS [alleged incapacitated persons.]”

As Professor Kohn, a noted elder law professor, writes:

“In light of these serious concerns, critics of guardianship and surrogate decision-making have suggested replacing that approach with “supported decision-making.” As a general matter, supported decision-making occurs when an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual’s words and behavior to determine his or her preferences. However, some advocates do not use the term “supported decision-making this broadly. Instead, they reserve the term for situations in which the person being supported has voluntarily entered into the arrangement, and these advocates use terms like facilitated decision-making and co-decision-making to describe other versions of supported decision-making.”

There is no one single model of supported decision making or even of such concepts as “person centered planning.” Some models involve court proceedings while others remain informal or lack legal enforceability. Different models of decision making are being developed and, in some instances, institutionalized by

legislation, in British Columbia and Saskatchewan in Canada, and Sweden, for example.

Among the many working definitions of “person-centered planning,” here (in part) is the one established by the U.S. Centers for Medicare and Medicaid Services (CMS):

“The individual directs the process, with assistance as needed or desired from a representative of the individual’s choosing. It is intended to identify the strengths, capacities, preferences, needs, and desired measurable outcomes of the individual. The process may include other persons, freely chosen by the individual, who are able to serve as important contributors to the process.” 42 C.F.R. 440.167 (2011).

In this country, some efforts have been made to integrate supported decision-making and person-centered planning into existing guardianship structures. For example, one of the recommendations made at the Third National Guardianship Summit in 2011 included:

“The guardian shall identify and advocate for the person’s goals, needs, and preference. Goals are what are important to the person about where he or she lives, whereas preferences are specific expressions of choice. First, the guardian shall ask the person what he or she wants. Second, if the person has difficulty expressing what he or she wants, the guardian shall do everything possible to help the person express his or her goals, needs, and preferences. Third, only when the person, even with assistance, cannot express his or her goals and preferences, the guardian shall seek input from others familiar with the person to determine what the individual would have wanted. Finally, only when the person’s goals and preferences cannot be ascertained, the guardian shall make a decision in the person’s best interest.”

What is the right approach to decision making by and for a person with diminished capacity? Do we need to follow a specific model, or are our laws sufficient? Those laws would include both guardianship/conservatorship as well as legal mechanisms that occur outside of court, like advance health care directives, powers of attorneys, representative payees, and other planning tools.

Questions for Workgroup Participants

In both the morning plenary session and during this workgroup working sessions, five invited panelists will help direct the discussion. The five panelists represent a variety of experiences and backgrounds in surrogate decision making. They include a mother who has limited guardianship authority for her mentally ill adult son, an experienced probate court clerk who was the caregiver and decision maker for her mother with dementia, a court appointed guardian for her mother with dementia who still resides at home with her husband (the guardian’s father)

and who makes decisions along with a court appointed professional conservator, an Elder Advocate given responsibility as guardian through the Ute Tribal Court for several tribal members with intellectual and cognitive disabilities, and an informal decision maker for a Sudanese refugee young man who is a paraplegic.

Questions listed below will be asked of the panelists. The workgroup will brainstorm on the most pressing issues facing surrogate decision makers and persons in need of help with decision making with a particular focus on what types of educational materials would best support the decision making challenges people confront. The hope is that through directed dialogue, the workgroup will be able to identify specific needs, whether those needs relate directly to guardianship, person-centered planning and thinking, or supported decision making. And, the workgroup will recommend methods that best provide the information and support decision makers need. Those methods might include virtual approaches, live training sessions, and published materials. The workgroup's task in the afternoon session will be to identify no more than four concrete action steps for WINGS to tackle.

Questions for the Guest Panelists

1. At what point did you realize you had to be the decision maker/caregiver?
2. How do you go about making decisions for or with the person you care for?
3. Who do you include in the decision making process and why?
4. Who do you consult in trying to make decisions and manage care?
5. What are the challenges you face in decision making?
6. What has been the best resource for you in helping you in your decision making and care management role?
7. What would help you or have helped you in terms of education/learning concerning your decision making and caregiving role?
8. What would be the best way for you to receive the education/information?
9. What else haven't we talked about that you would like to share with us?

Background Reading (this is not meant to be a comprehensive list but it does contain the resources noted above in passing)

Utah Resources

Utah State Courts website pages on guardianship and conservatorship,
<http://www.utcourts.gov/howto/family/gc/>

Utah State Courts Ad Hoc Committee on Probate Law and Procedure 2009 Report,
<http://www.utcourts.gov/committees/adhocprobate/Guardian.Conservator.Report.pdf#page=9>

Utah Department of Human Services, Office of Public Guardian, A Guide to Guardian Services in Utah,
http://opg.utah.gov/pdf/guide_to_guardian_services.pdf

Alzheimer's Association Utah Chapter, <http://www.alz.org/utah/index.asp>

Guardianship Associates of Utah, <http://guardianshiputah.org/>

Guardian and Conservator Services, LLC,
<http://guardianconservatorservices.com/>

NAMI Utah, <http://www.namiut.org/>

Academic Publications

Stanley S. Herr, *Self-Determination, Autonomy, and Alternatives for Guardianship*, in The Human Rights of Persons with Intellectual Disabilities: Different but Equal (Stanley S. Herr et al. eds., 2003).

A. Frank Johns, *Person-Centered Planning in Guardianship: A Little Hope for the Future*, 2012 Utah L. Rev. 1541(2012),
<http://epubs.utah.edu/index.php/ulr/article/view/840/648>

Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?* 117 Penn St. L. Rev.1111 (2013),
[http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20\(final\)%20\(rev2\).pdf](http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20(final)%20(rev2).pdf)

Doug Surtees, *The Evolution of Co-Decision-Making in Saskatchewan*, 73 Sask.L.Rev. 75 (2010).

Symposium, *Third National Guardianship Summit Standards and Recommendations*, 2012 Utah L. Rev. 1191 (2012),
<http://epubs.utah.edu/index.php/ulr/article/view/833/642>

National and International Resources

National Guardianship Association, Inc., <http://www.guardianship.org/>

National Guardianship Association, Inc., *Guardianship Standards*,
http://www.guardianship.org/guardianship_standards.htm

NIDUS, British Columbia, Canada, <http://www.nidus.ca/>

Brenda K. Uekert & Richard Van Duizend, *Nat'l Ctr. For State Courts, Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform* 107 (2011),
http://www.guardianship.org/reports/Uekert_Van_Duizend_Adult_Guardianships.pdf

United Nations Enable, *Handbook for Parliamentarians on the Convention of Rights of Persons with Disabilities*,
<http://www.un.org/disabilities/default.asp?id=212>.

Useful Legal Terms and Acronyms

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Acceptance of appointment

A written document signed by the guardian/conservator confirming acceptance of the order to serve as guardian/conservator of the protected person. This document must be filed with the court.

Advance health care directive

A written document or oral statement by an adult that expresses the adult's wishes for health care treatment in case the adult is, in the future, not able to express current wishes. Utah law recognizes a standard advance health care directive form. Utah's form provides for the possibility of an expression of wishes as well as for the appointment of a health care agent. Utah law also recognizes a hierarchy of surrogate decision makers in case the adult has never issued an advance health care directive and is now unable to express current wishes.

Affidavit

A written and sworn statement witnessed by a notary public or other official with the authority to administer oaths. Affidavits may be admitted into evidence.

Agent

An adult appointed by another adult ("the principal") in a power of attorney, executed according to law. The agent's legal authority is limited to the authority granted by the principal.

Annual accounting

The yearly financial report of the protected person's estate that the guardian—or conservator if one has been appointed—must file with the court.

Annual report

The guardian's yearly report to the court on the well being of the protected person. The annual report shows the protected person's status and care and alerts the court to any changes.

Appointment

The designation of a person by the court to be a guardian or conservator and to discharge the duties of that office.

Code of Judicial Administration

The rules established by the Utah Judicial Council governing administrative practices and procedures of the state judiciary.

Conservator

A person or institution appointed by the court to manage the property and financial affairs (“estate”) of a protected person. A guardian is a person or institution appointed by a court to make decisions about the care of another person who is in need of continuing care and protection, such as a minor child or an incapacitated adult. Sometimes the same person is appointed to both roles. If no conservator is appointed, the guardian has some of the responsibility of a conservator.

Conservatorship

The court proceeding to appoint a conservator and any subsequent proceedings. A conservatorship exists when the court has appointed a conservator for a person in need of protection.

Court visitor

A person who is trained in law, nursing, or social work and is an officer, employee, or special appointee of the court with no personal interest in the proceedings. The judge may appoint a visitor to inquire about and observe a protected person's circumstances to provide a more complete and nuanced picture of that person's life.

Emergency guardianship

An extraordinary court proceeding that may result in the appointment of a temporary guardian to provide for the immediate care and custody of a person for a specified period not longer than 30 days. If a temporary guardian is appointed, the court must hold a hearing within five days. Until the full hearing and order of the court, the temporary guardian is charged with the care and custody of the protected person and must not permit the protected person to be removed from the state. The authority of any permanent guardian previously appointed by the court is suspended so long as a temporary guardian has authority. A temporary guardian may be removed at any time, and must obey the court's orders.

Estate

All of the protected person's assets and liabilities, including all real property (land) and personal property (things).

Evidence

Testimony, records, documents, material objects, or other things presented at a hearing to prove the existence or nonexistence of a fact.

Fiduciary

A person who has assumed a special relationship to another person or another person's property, such as a trustee, administrator, executor, lawyer, or guardian/conservator. The fiduciary must exercise the highest degree of care to maintain and preserve the person's rights and/or property which are within his/her charge.

Final accounting

The last financial accounting that must be filed with the court by the guardian or conservator upon the death of the protected person, resignation of the guardian or conservator, or termination of the guardianship/conservatorship.

Guardian

A person or institution appointed by a court to make decisions about the care of another person who is in need of continuing care and protection, such as a minor child or an incapacitated adult. A conservator is person or institution appointed by the court to manage the property and financial affairs (“estate”) of a protected person. Sometimes the same person is appointed to both roles. If no conservator is appointed, the guardian has some of the responsibility of a conservator.

Guardian ad litem

A lawyer appointed by a court to look after the interests of a minor child during court proceedings, or to look after the interests of an adult in conservatorship proceedings.

Guardianship

The court proceedings to appoint a guardian and any subsequent proceedings. A guardianship exists when the court has appointed a guardian for an incapacitated person.

Hearing

A formal proceeding (generally less formal than a trial) with issues of law or of fact to be heard and decided.

Health care decision making capacity

An adult's ability to make an informed decision about receiving or refusing health care, including:

- (a) the ability to understand the nature, extent, or probable consequences of health status and health care alternatives;
- (b) the ability to make a rational evaluation of the burdens, risks, benefits, and alternatives of accepting or rejecting health care; and
- (c) the ability to communicate a decision.

Utah Code Section 75-2a-103(13).

Incapacity

“Incapacity” means that an adult's ability to:

- receive and evaluate information; or
- make and communicate decisions; or
- provide for necessities such as food, shelter, clothing, health care, or safety

is impaired to the extent that s/he lacks the ability, even with appropriate technological assistance, to meet the essential requirements for financial protection or physical health, safety, or self-care. Incapacity is a judicial determination, and is measured by the person’s functional limitations.

Utah Code Section 75-1-201.

Informed consent

A person's agreement to allow something to happen that is based on a full disclosure of facts needed to make the decision intelligently, i.e., knowledge of risks involved, alternatives, etc.

Interested person

As defined in the Utah Uniform Probate Code, an "interested person" includes heirs, devisees, children, spouses, creditors, beneficiaries, and any others having a property right in or claim against a trust or the estate of a decedent, or protected person. It also includes persons having priority for appointment as personal representative, other fiduciaries representing interested persons, a settlor of a trust, if living, or the settlor's legal representative, if any, if the settlor is living but incapacitated. The court can determine who is an interested person in a particular case, so the meaning may vary from one case to the next.

Inventory

A detailed list of property and other assets with their estimated or actual values. A guardian or conservator must file an inventory with the court within 90 days after appointment.

Least restrictive alternative

A mechanism, course of action, or environment that allows the person to live, learn, and work in a setting that places as few limits as possible on the person's rights and personal freedoms as appropriate to meet the needs of the person.

Letters of guardianship/conservatorship

The document issued by the court authorizing the appointment of the guardian/conservator and the extent of the powers of the guardian/conservator to act on behalf of the protected person.

Limited guardianship

A guardianship that orders the guardian to have decision making powers limited to the specific needs of the protected person. A limited guardianship order describes the guardian's decision making authority over the protected person. Utah law presumes that the court will order a limited guardianship.

Person centered planning

A variety of approaches designed to guide change in a person's life. This type of planning is carried out in alliance with the person, their family and friends and is grounded in demonstrating respect for the dignity of all involved. Recognized approaches seek to discover, understand, and clearly describe the unique characteristics of the person, so that the person has positive control over the life s/he desires and finds satisfying, is recognized and valued for contributions (current and potential) to the person's communities, and is supported in a web of relationship, both natural and paid, within the person's communities.

Petition

A document filed to initiate a case, setting forth the alleged grounds for the court to take jurisdiction and asking the court to grant the petitioner's request.

Petitioner

The person who files the petition, asking the court to do something. In guardianship proceedings, the petitioner is often, although not always, the person asking to be appointed as guardian.

Plenary guardianship

A guardianship that orders the guardian to have all decision making powers for the protected person allowed by law. Also known as a "full" guardianship.

Power of attorney

A written document in which one person, as principal, appoints another as agent, and gives that agent authority to do certain specified acts or kinds of acts, on behalf of the principal. Completing a power of attorney document does not require a court proceeding. The principal should sign the document before a notary public.

Principal

The person who has given authority to another ("agent") to act for the principal's benefit and according to the principal's direction and control.

Private, public and protected records

Most records filed in the district courts and justice courts are "**public**" records, meaning that anyone who asks can view the record and make a copy of it. Many public records are available on the court's website. Some records are "**private**," meaning that only the parties, their lawyers, and a few others can view and copy the record. Less common are "**protected**" records, meaning also that only the parties, their lawyers and a few others can view and copy the record. Records in guardianship and conservatorship proceedings are private, except that the court's orders and letters of appointment are public.

Protected person

The person in a guardianship proceeding who has been determined by the court to be legally incapacitated and in need of a guardian. Also, the person in a conservatorship proceeding who has been determined by the court to be in need of a conservator.

Representative payee

If an agency, such as the US Department of Veterans Affairs or the Social Security Administration, pays benefits to the protected person who has been found by the court to be incapacitated, the agency must appoint a representative payee to receive the payments. This appointment is separate from the court-appointed guardian and conservator. Any person wishing to serve as the

representative payee must apply to the agency that provides the benefits. In most cases, the agency will appoint the court-appointed guardian or conservator as representative payee. However, the agency providing the benefits has the authority to appoint any person it chooses to be the protected person's representative payee. Once appointed by the agency, the representative payee has the authority to receive and handle the benefits for the protected person.

Respondent

The person who responds to a petition. In a guardianship/conservatorship proceeding, the person who is alleged to be incapacitated and in need of protection.

Standard of proof

There are three standards of proof in most court proceedings:

Beyond a reasonable doubt (the highest standard) means that the evidence must be firmly convincing about the truth of the fact to be proved. This standard applies in all criminal and juvenile delinquency cases.

Preponderance of the evidence (the lowest standard) means that the evidence must show that the fact to be proved is more likely true than not true. This standard applies in most civil cases.

Clear and convincing evidence (a middle standard) means that the evidence must leave no serious doubt about the truth of the fact to be proved. This standard applies in some civil cases, including deciding whether a person is incapacitated.

Standards for decision making (based on National Guardianship Association Standards)

Substituted judgment

The principle of decision making that substitutes the decision the person would have made when the person had capacity as the guiding force in any surrogate decision the guardian makes. Substituted judgment promotes the underlying values of self determination and well being of the person. It is not used when following the person's wishes would cause substantial harm to the person or when the guardian cannot establish the person's goals and preferences even with support.

Best interest

The principle of decision making that should be used only when the person has never had capacity, when the person's goals and preferences cannot be ascertained even with support, or when following the person's wishes would cause substantial harm to the person. The guardian should

consider the least intrusive, most normalizing, and least restrictive course of action possible to provide for the needs of the person.

Statute

A law passed by the Utah state legislature.

Supported decision making

As a general matter, supported decision making occurs when an individual with cognitive challenges is the ultimate decision maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behavior to determine his or her preferences.

Temporary guardian

A person or entity appointed by the court to have temporary decision making authority for a person if an emergency exists, or if an appointed guardian is not effectively performing his or her duties and the protected person's welfare requires immediate action. The appointment of temporary guardian is for a specified time not to exceed 30 days. The court must hold a hearing within five days.

Trust

A transaction in which the owner (called the trustor or settlor) of real property (land) or personal property (things) gives ownership to a trustee, to hold and to manage for the benefit of a third party (called the "beneficiary").

Trustee

A fiduciary in whom an estate, interest, or power is vested, under an express or implied agreement, to hold and to manage for the benefit of another.

Utah Code

The collection of all statutes enacted by the Utah legislature.

Utah Rules of Civil Procedure

The rules governing court procedures in all actions of a civil nature.

Utah Uniform Probate Code

The statutes that govern probate matters including administration of a decedent's estate, guardianships, conservatorships, trusts, and advance healthcare directives.

Acronyms

APS

Adult Protective Services

AAA

Area Agency on Aging

AARP

(formerly known as the American Association of Retired Persons)

AoA

Administration on Aging

AOC

Administrative Office of the Courts

CGC

Center for Guardianship Certification

DAAS

Division of Aging and Adult Services

DHS

Department of Human Services

DLC

Disability Law Center

DSAMH

Division of Substance Abuse and Mental Health

DSPD

Division of Services for People with Disabilities

JFS

Jewish Family Service

HIPAA

Health Insurance Portability and Accountability Act of 1996

LTCO

Long Term Care Ombudsman

NAMI

National Alliance on Mental Illness

NGA

National Guardianship Association

OPG

Office of Public Guardian

SSA

Social Security Administration

ULS

Utah Legal Services

VA

US Department of Veterans Affairs