

Rethinking Guardianship: Building a Case for Less Restrictive Alternatives

First Year Report

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Executive Summary

Although the Guardianship Statute (GS Chapter 35A) asserts that guardianship should seek to preserve the maximum exercise of rights, policy and practice often produce results that fall short of that ideal.

In particular, there are few widely-recognized alternatives to adult guardianship, and those that exist are not always honored. These and a number of other problems are demonstrated in both data and the personal experience of advocates and human services professionals who have come together in the Rethinking Guardianship Workgroup.

Complex problems, such as those associated with guardianship, require new approaches. Like the WINGS guardianship projects in a number of states, the Rethinking Guardianship initiative has chosen a Collective Impact framework from which to build on the progress made by previous guardianship initiatives, and effect change on multiple facets of guardianship, as represented by the diverse interests of the workgroup.

To address these issues and fulfill its contractual purpose, in partnership with the NC Division of Aging and Adult Services, the Jordan Institute for Families has:

1. **Brought together a diverse and committed workgroup** that continues to broaden participation to a wider range of stakeholders. The group is working toward sustainable change, but it is also anticipated that the group will be sustainable beyond the three years of funding;
2. **Begun building a knowledge base of best practices** in guardianship and its alternatives by sharing literature in the workgroup's Dropbox folder; hearing presentations from a variety of internal and external experts; communicating with the

WINGS states; and engaging in group exercises during meetings to build on the wide and varied experience of the workgroup;

3. **Begun building a collection of relevant data** to support innovative approaches to guardianship alternatives, beginning with surveys of the clerks of superior court and the use of the public data maintained by the Administrative Offices of the Court. This will be complemented by both additional data and the rich stories of self-advocates and family advocates.

In addition to teaching about the Collective Impact framework at every meeting, the Jordan Institute consistently modeled the five elements of Collective Impact at a level appropriate for the first year, which is considered the developmental year of the Collective Impact process.

In the second, or formative year of the initiative, the workgroup will continue applying the Collective Impact framework on both the state and local level. Year two activities will include the following.

Locally:

- Identifying one or more local pilots
- Providing technical support and some initial "backbone" infrastructure support to these pilots
- Appointing a subcommittee to act as liaison between the state and local levels

Statewide:

- Conducting longitudinal analysis with AOC data
- Refining a common agenda
- Identifying and beginning to implement mutually reinforcing activities from the different sectors within the workgroup

Rethinking Guardianship: First Year Report

Adult guardianship is a legal process surrounded by a host of complex problems, resource challenges, and unintended consequences. It exists to protect our most vulnerable citizens, but in the process too often strips them of the right to make the most basic decisions for themselves—such as where they will live and what they will do in the course of a day.

“Limiting the rights of an incompetent person by appointing a guardian for him should not be undertaken unless it is clear that a guardian will give the individual a fuller capacity for exercising his rights.”

“Guardianship should seek to preserve for the incompetent person the opportunity to exercise those rights that are within his comprehension and judgment, allowing for the possibility of error to the same degree as is allowed to persons who are not incompetent. To the maximum extent of his capabilities, an incompetent person should be permitted to participate as fully as possible in all decisions that will affect him.”

—GS Chapter 35A. Subchapter II. Article 4. 35A-1201 Purpose. (a4 and a5)

Introduction

Although the Guardianship Statute (GS Chapter 35A) asserts that guardianship should seek to preserve the maximum exercise of rights (see sidebar), the process is not well designed to fulfill that purpose. Implementation of the process involves many well-informed and caring people in a variety of public and private sectors. Yet, almost everyone associated with the process— whether families, self-advocates, service providers or clerks of court— has at least one painful story or issue to relate:

- Parents of young adults with intellectual disabilities are routinely instructed by schools to seek guardianship once a child turns 18—depriving their children of their most basic rights—without assessment of the young adults’ abilities to function with less drastic supports for decision making.
- Too few adults put powers of attorney, health care power of attorney, mental health powers of attorney, or other legal documents into place while they are competent, to provide for their choice of decision makers and prevent guardianship in the eventuality that they become incompetent through age, illness, or injury. Even fewer are familiar with the use of non-legal supports for decision making as an alternative to legal instruments.
- Sometimes the person with a correctly executed power of attorney is told by hospital staff or attorneys that they cannot make some medical decisions without seeking guardianship.
- Hospitals sometimes seek guardianship for hard-to-discharge patients because “we need the bed”, thinking,

incorrectly, that guardianship will make additional resources for discharge available.

- Sometimes people petition for guardianship because of conflicts with other family members about money, because they disapprove of that family member's choices, or because they think guardianship will result in more services being available to their family member.
- The quality of evidence and assessments, on which the crucial decision to declare someone incompetent is made, is inconsistent from case to case and county to county.
- People with mental health conditions sometimes experience fluctuating periods of competency; guardianship is poorly suited to ebb and flow with these changes, leaving people under guardianship even when they are fully competent.
- Public guardians have caseloads so large that they have difficulty meeting the standard of visiting the person under guardianship as often as they should, or even as often as the standards require. In practice, this almost always results in the person under guardianship being placed in some kind of residential care, which is expensive and might not otherwise be needed.
- Recent changes in the law have led to a slight increase in petitions for restoration of rights, but the number is still very small.
- Families want the best for their loved ones, but are often not aware of alternatives to guardianship. They may not know where to get reliable information on available alternatives or best practices.

A few of these issues are highlighted in the story below.

The Story of Ms. Williams

Deborah Williams was a 31 year-old woman from Creedmoor, North Carolina. She worked for several years as a registered nurse, having earned her degree at the University of North Carolina in Chapel Hill. She was described as a gentle person who was motivated to serve others. As a survivor of sexual assault and after experiencing the loss of her mother at an early age, she battled severe depression.

After surviving a stroke due to a history of substance use, Ms. Williams had difficulty speaking clearly and lost her job. Ms. Williams's father petitioned for incompetency,

declaring, “I do not know what else to do. The doctors say that she is manic-depressive.” He expressed how his life has been burdened by her mental illness and troublesome behavior. She also posed a risk to the community for driving while intoxicated. The father’s intention was to get his daughter “the help she needs,” and assumed that guardianship meant access to social services and care. In the past, he made an effort to connect her to outpatient psychiatry, but neither Ms. Williams nor her father could afford the prolonged cost. The Guardian ad Litem met Ms. Williams and confirmed that she had been living on the street “by choice” and “smelled like booze.”

She was declared incompetent and a public (Department of Social Services) guardian of the person was appointed for her due to her ongoing experience of depression, social isolation, and recurrent homelessness. The guardian had a master’s degree in special education and previously worked at the County Medicaid office for a few years. He was relatively new; he had applied for the guardian position because it offered an increase in salary and because he felt a personal affinity for older adults. He had not realized the work would entail intensive case management for younger adults with mental health and substance use challenges.

He found appropriate housing and a mental health provider, but these were not close to Ms. Williams’s home so she was relocated to an unfamiliar neighborhood more than an hour’s drive from any friends or family. At a later date, she was admitted to an in-patient psychiatric unit for a suicide attempt, where her diagnosis included substance use disorder, bipolar disorder, major depressive episode, and borderline personality disorder. Not discounting the significance of her history of depression and substance use, the primary diagnosis was determined as bipolar II disorder, depressive type. When she was deemed safe and ready for discharge, she was released to her apartment, where she began self-medicating with alcohol. The hospital psychiatry team kept Ms. Williams’ guardian well informed throughout the course of her treatment and aftercare arrangements; however, the guardian also had 44 other wards for whom he was responsible. (“Wards” is the legal term for people who have a guardian. Many people object to this term, but it is used by lawyers and in some service agencies.) Arguably, at a time when Ms. Williams was most vulnerable, she had no formal support in those few weeks after her discharge.

After visiting “more demanding” and “difficult” wards, the guardian saw Ms. Williams. The visit was impromptu, and she was flummoxed. He had not paid her rent or phone bill, and she barely had money for groceries. She expressed her outrage with the bureaucratic and paternalistic hold he had on her life. The guardian was equally frustrated, and made a note to tend to her bills as soon as possible. In the interim, Ms. Williams kept drinking. The guardian was unaware of the quantity of alcohol she was consuming and had to hurry to an appointment at Central Regional Hospital for another client that day.

A few weeks later—two years after the initial declaration of incompetence—the guardian received a call from the police. Ms. Williams was found in a hotel near her apartment. She had been dead for 12 hours.

(Names and a few details have been changed for reasons of confidentiality.)

Solving these complex problems and the unintended consequences associated with adult guardianship requires new

approaches. Some of the authors of this report and probably most of its readers have served on one or more committees to address guardianship reform and some positive changes have been enacted. Still, the issues described continue, largely unabated.

As we see continued growth in the numbers of people with intellectual and other developmental disabilities, people who reach ages 80 and older, as well as the number of those with autism spectrum disorders, mental health diagnoses, and/or substance abuse problems, the cost in money, time, and emotional pain grows larger and larger. We cannot afford to continue to reuse the same old approaches that have been tried and found ineffectual.

The *Rethinking Guardianship* initiative has adopted the Collective Impact approach to help bring a new mindset to this set of ongoing issues aimed at effecting lasting systems change. In recent years almost every project has acknowledged and implemented the truth that complex problems can only be solved or ameliorated by collaboration among multiple stakeholders. However, Collective Impact goes beyond mere collaboration by broadening the diversity of stakeholders— to include self-advocates, families, policymakers, business, education, service providers, social services, aging services, justice, and law among others—and providing a set of tools to guide and focus initiatives on a wide variety of topics.

As the list of issues that opens this report suggests, Collective Impact—or any kind of collaboration on guardianship reform—is complicated by the variety of issues that affect different stakeholders. At a minimum, these include:

- Preventing unnecessary guardianship; improving the availability of assessments and other evidence that clerks of superior court use to make guardianship decisions;
- Educating families and individuals, including those with disabilities, about alternatives to guardianship and, when guardianship is the only option, providing information about the procedures for seeking guardianship, the responsibilities that come with obtaining it, and the choices that continue to belong to the individual who has a guardian.
- Reducing the unreasonable caseload size of public guardianship workers in county departments of social services and the consequent limits to the services that they can provide; and

“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.”
—Kania & Kramer, 2011

- Addressing the lack of mental health and other resources needed to either prevent guardianship for people with severe mental illness or to make guardianship safer and more responsive to the needs of this group.

The first year of the initiative has brought together a diverse group of stakeholders, including self-advocates and their family members as well as policymakers, legislators, faculty of public and private universities, private nonprofits, for-profits, and associations. Together, these stakeholders represent a broad and overlapping population of people at risk for being declared incompetent. Self-advocates and family advocates at the table represent the intellectual and developmental disability (IDD), aging, and mental health communities.

This report documents the activities, accomplishments, and findings of the workgroup to date and demonstrates how the collective impact framework supports the initiative's purpose, as articulated by the North Carolina Council on Developmental Disabilities (NCCDD).

Robyn Dorton's Story of How She Got Her Own Guardianship

Robyn is an active self-advocate member of the Rethinking Guardianship Workgroup

"I was put into foster care from age 15 to 18. From 18 on I had a case manager who was enthusiastic about getting me out of group homes and on my own. I started within my circle of friends. Your circle is a group of people that can help a person with something small and something large in their life.

First we planned how to go about it. We started from my case manager. It took from the time I was 18 until I was 24. There were some bumps. I was told I couldn't get my guardianship the way the system was set up because of reasons, but they weren't giving [me] reasons. I had to go through lots of red tape.

At the time, I didn't know that my guardian was going to hand over my guardianship. Then I was in court and I heard, "Ms. Dorton, you are your own guardian." I was feeling overwhelmed! We had a party and a half!

Even though I'm my own guardian, I still have people to help me with things. Like with money—I know myself well and I have a representative payee. I got my guardianship on September 5, 2002 and I have been living on my own since 1996.

If you don't have that extra backbone, then you are out of luck. I had motivation and drive and I didn't back down."

Adapted from: Zuver, D., Dorton, R., Finks, W., & Fisher, K. Acting for advocacy. In: Marshall, C.A., Kendall, E., Banks, M., & Gover, R.M.S. (Eds.) *Disabilities: Insights from Across Fields and Around the World*, 3 volume book set. Westport, CT: Praeger Press, 2009

Why a Different Approach?

The Price of Failure Is Not Acceptable

No one keeps a record of how many adults in the state currently have guardians. Based on the number of public guardians in 2013 and the percentage of all people adjudicated incompetent who have public guardians appointed (30%), obtained from *Public Guardianship Ad-Hoc Workgroup Report* (NC DAAS, 2013), we estimate that 15,690 NC adults currently have public or private guardians. (Private guardians are almost always family members, but may also be friends of the person assigned a guardian.) That is roughly 2 of every 1,000 adults in the state.

In state fiscal year 2014-15, there were 3,648 adults in North Carolina who were ruled incompetent and appointed guardians.

— Administrative Offices of the Court VCAP Data

The same report projects that, if nothing is changed, approximately 7,010 North Carolinians will have public guardians in 2017. This translates into an estimated 23,367 people with guardians of any kind.

Approximately 15,690 NC adults currently have public or private guardians. That is roughly 2 out of every 1,000 adults in the state.

The financial costs of public guardianship can become quite significant. In two recent studies public guardianship costs in 2007-08 in Florida were \$2,648 per client, and were \$3,163 per client in 2008-11 in Washington (Schmidt, 2015). Estimates from the *Public Guardianship Ad-Hoc Workgroup Report* would place North Carolina at \$3,400 per client, with a total spending of \$17 million for public guardianship in fiscal year 2013. It is doubtful that the cost of private guardianship is much less, but it is never computed because it is borne by families rather than taxpayers.

North Carolina spent \$17 million for public guardianship in state fiscal year 2013.

Although the financial cost of providing public guardians can be substantial, the cost of *not* providing appropriate guardians for those in need is also significant. In recent studies Virginia saved \$5.6 million in health care costs for 85 patients, Florida saved \$3.9 million in health care costs in one year, and a New York hospital lost \$13 million during nine months for 400 patients in need of guardianship (Schmidt, 2015). With current caseload size public guardians cannot provide the level of service that makes these savings possible.

Even more important than the financial costs of guardianship is the issue of quality of life for the person under guardianship. In a 30-month Washington State study, 21% of people with guardians who had small caseloads and could deliver optimal management of services showed an improvement in self-sufficiency. Unfortunately, very little rigorous comparison

research between adults with and without guardians has been conducted to determine how their quality of life outcomes may differ (Schmidt, 2015). The same may be said comparing people with family guardians and non-family guardians.

For some, guardianship will continue to be the best, last option. Others will suffer one or more of the unintended consequences outlined in the introduction. The cost of business as usual is reducing quality of life and inflating the burden of public funding.

Recent State Focus on Guardianship Reform

In the past two years North Carolina has convened several working groups focused on the guardianship system and needed reforms. In 2013 it started with the Public Guardianship Ad-Hoc Workgroup sponsored by the Division of Aging and Adult Services (DAAS). In early 2014 the Ad-Hoc Group's work was built upon by the Joint Legislative Oversight Committee on Health and Human Services Subcommittee on Public Guardianship. Later in 2014 the Department of Health and Human Services (DHHS) produced a final report on public guardianship which drew from the first two groups' work. These three reports built on each other and showed significant agreement about the current problems with public guardianship and in their recommendations for improvements.

The first component listed in DAAS's model plan is to promote alternatives to guardianship so that people are supported without the need of a guardian.

A notable recent change in guardianship law, identified by the second two reports, is that when someone was in need of public guardianship clerks used to be able to appoint Local Management Entities (LMEs) or other agencies as the guardians, based on the clerk's discretion. Legislative changes now state that only DSS agencies are eligible to be "disinterested public guardians." This change was made to avoid conflict of interest that arose from an entity being both a service provider and guardian for the same ward. However, this change has brought new challenges, such as increased difficulty for guardians accessing services for the people to whom they are assigned (specifically those provided by Local Management Entities or Managed Care Organizations) and increased burden on DSS agencies in their role as guardian. Additionally, this change has not fully addressed the conflict of interest that arises when DSS is guardian to an adult and that adult's children are also in DSS custody through child protective services (Public Guardianship Subcommittee Final Report; March, 2014).

A legislative change that the Subcommittee on Public Guardianship recommended was that North Carolina General Statute 35A-1242 be revised so that status reports on wards include more comprehensive information, including information about efforts to restore competency or seek alternatives to guardianship. The statute change went into effect October 1, 2014.

The Joint Legislative Oversight Committee on Health and Human Services, in their Final Report on the Examination of Ways to Improve the Public Guardianship System (October, 2014), directed DAAS to develop a model plan that reduces the use of public guardians. The first component listed in DAAS's model plan is to promote alternatives to guardianship so that people are supported without the need of a guardian.

This report also suggested working with the Administrative Office of the Courts (AOC) to make needed modifications to the Civil Case Processing System, which the office labels VCAP, for the purpose of tracking guardianship cases more effectively (Final Report on the Examination of Ways to Improve The Public Guardianship System; October, 2014). The Rethinking Guardianship Workgroup has not requested that the AOC make any modifications to the VCAP system. However, it has requested a large amount of data which is being analyzed for better understanding of guardianship, and it has identified some potential changes that could be made to the VCAP system to improve guardianship tracking. (For a listing of all recommendations from the three previous initiatives, see Appendix A.)

These three North Carolina work groups did not appear to include self-advocates or family advocates in their membership. This may have been because all three of these efforts were focused on *public* guardianship and the majority of guardians of people with IDD are family members.

The Rethinking Guardianship Workgroup, by contrast, is concerned about the problems of both public and family guardianship. It includes many entities and individuals who were involved in producing these previous three reports, as well as people who were not included. Although the common agenda of the workgroup is still being developed, their discussions demonstrate consensus that promoting alternatives to guardianship is the foundation for improving the

guardianship system with the help of the Collective Impact tools.

In addition to these group activities, Representatives Farmer-Butterfield, R. Turner, Hurley, and Meyer introduced House Bill 861 in the 2015 session. This bill called for the Legislative Research Commission to study whether NC statutes should be amended to include supported decision making. Unfortunately, this bill was referred to committee on April 15, 2015 and never came to the floor.

Lessons from Others States—WINGS

In 2011 the National Guardianship Council convened the Third National Guardianship Summit. It was sponsored and co-sponsored by a variety of organizations and associations representing law, aging, and disability concerns—including the ARC and the National Disability Rights Network. One of the most influential recommendations from that summit was that all states should establish court-community partnerships. Out of this recommendation came an initiative that called itself the “Working Interdisciplinary Networks of Guardianship Stakeholders” or “WINGS” (National Guardianship Council, 2014).

The advantages of this initiative over previous guardianship reform efforts, as described by the Council, are:

- It provides a mechanism for ongoing, grounded evaluation of guardianship practice;
- It continues to move from recommendations and advocacy to actual implementation, reassessment, and modification;
- It facilitates ongoing communication among stakeholders; and
- It contains “the essential gamut” of stakeholders.

In addition, the WINGS initiative called for the use of the Collective Impact framework because of the promising results this set of tools was getting with other social problems.

The goal is for all states to have WINGS. In 2013, the first four states became part of the initiative and in 2015 an additional six were added. This does not include three states that have developed similar partnership groups without becoming official WINGS states.

“Over the past 25 years, adult guardianship reform recommendations repeatedly have urged the creation of court-community partnerships.”
—National Guardianship Network

“Such broad-based, collaborative working groups can drive changes that will affect the ways courts and guardians practice, and improve the lives of people who have or may need guardians.”
—National Guardianship Network

Our North Carolina initiative has been in communication with the WINGS states, and has received a presentation from one of their experts. It has also embraced the framework of Collective Impact. The decision about whether to apply for status as a WINGS state has not yet been made by the workgroup.

The Collective Impact Framework

There are five key elements of the Collective Impact framework to address complex problems. These are implemented over the course of three to five years.

In common with other collaborative approaches, Collective Impact requires a diverse group of stakeholders. In fact, it goes beyond this minimum to recommend that stakeholders represent multiple different “sectors,” not just different organizations in the same sector. Sectors might include government, human services agencies, businesses, local foundations, nonprofits, people served, advocacy organizations, education, all varieties of health care, faith communities, and others (FSG, 2015). Further, these stakeholders must realize that they are affected by the problem they intend to address and that it cannot be solved by a single system.

The five key elements of Collective Impact, identified by Kania and Kramer (2011), are:

- Common agenda;
- Continuous communication;
- Mutually reinforcing activities;
- Shared measurement; and
- Backbone infrastructure.

The first year of a Collective Impact initiative is called the “developmental stage.” During that time, attention is given to developing the prerequisites, providing backbone infrastructure and assuring continuous communication, while working toward solidifying a common agenda and beginning to look for the most promising mutually reinforcing activities. When the common agenda and activities have been set (understanding that there will continue to be modifications as efforts do or do not work), the group can move forward with selecting potential measurements and developing a system for sharing these data (Parkhurst & Preskill, 2014).

“In complex problems,

- *No one actor alone can solve the problem.*
- *There are gaps and silos in the system.*
- *There is lack of coordination among actors.*
- *There is a need for new policies or significant policy change.*
- *There is need for innovation or new solutions.”*

—FSG, 2015

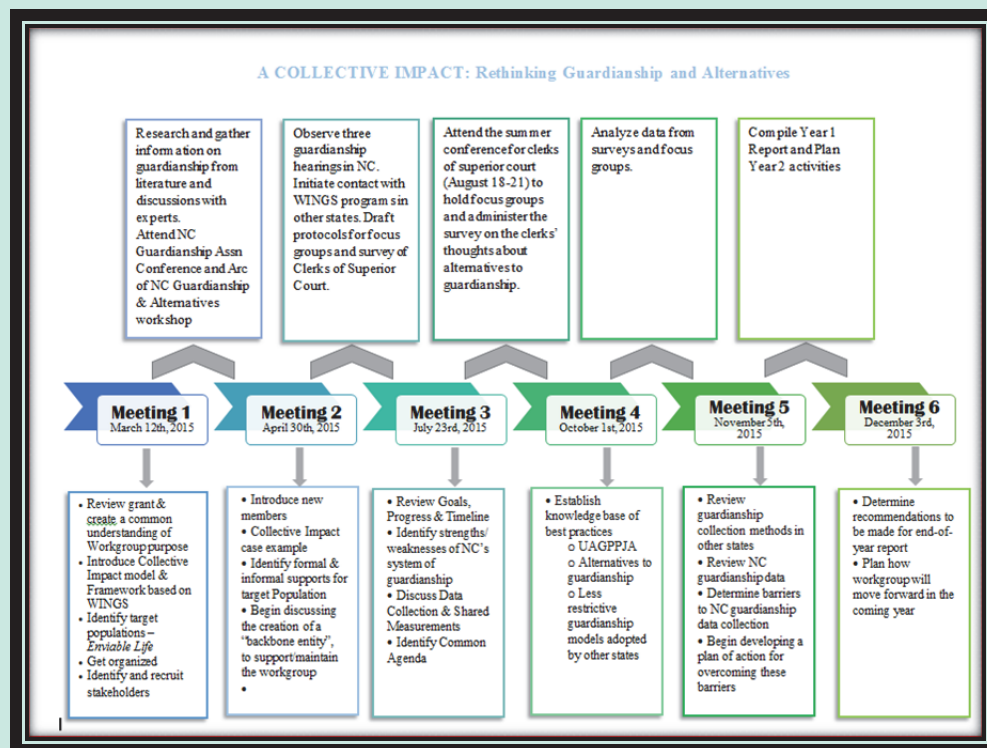
First Year Accomplishments— Our Purpose in Action

Purpose of this Initiative

The North Carolina Council on Developmental Disabilities charged this initiative with three purposes—

1. To create a sustainable workgroup that will create long-term support for guardianship systems change by building a knowledge base of best practices in guardianship and its alternatives.
2. To build a collection of relevant data to support innovative approaches to guardianship alternatives.
3. To address changes needed to North Carolina’s current guardianship statutes, policies, and practices on an ongoing basis.

This section examines progress on each of our purposes separately, then goes on to show how we have accomplished this while teaching and modeling each of the five requirements of the Collective Impact model. Because in practice these purposes are not pursued or met separately, the timeline shows the broad strokes of activities in and out of the workgroup’s meetings.



We created a diverse and sustainable workgroup committed to guardianship systems change

Families and self-advocates along with fifty people from a variety of agencies were invited to the initial meeting on March 12, 2015 (including DAAS, but not including the Jordan Institute for Families staff facilitating and providing backbone support for the meeting); 36 of those invited attended that meeting (72%). Over the eight months since that time, new invitees have been suggested and people hearing about the group have invited themselves, so the group has grown. The invitation list for the December 3, 2015 meeting was 76 people (excluding project staff and facilitators).

Of these, 39 non-staff have attended at least two of the five meetings held before the drafting of this report; the average attendance over the 5 meetings was 35. In addition, a number of people unable to attend because of schedule conflicts or other restrictions have kept in touch and have expressed appreciation for access to the literature and presentations made available to them.

Because the number of potential attendees has grown over time, it is not possible to calculate the percentage of current members attending, but there is clearly a core group of dedicated participants. Although the energy and interest in the meetings is frequently remarked upon, this cannot be quantified. However, there is some support besides attendance for the level of engagement in this group.

Of course we plan for the actions of the Workgroup to be sustainable, but we are also planning to find a way to sustain the workgroup itself after the initial 3 years of funding is over.

A brief year-end survey, requesting feedback on the first year's work, was sent out electronically and given out at the December meeting to participants who were not affiliated with the Jordan Institute for Families and were not newcomers to the meeting. With only three days to respond, 20 people gave their feedback. The form consisted of three open-ended questions and two items to rate on a five-point scale.

To the question, "How much promise do you see in this "collective impact" approach to solving the complex problems associated with guardianship?" (on a 5-point scale in which 1=very little promise, and 5="very great promise). The mean answer was 4.4 (median 5). This represented 12 people (60%)

"Six hours on the road one day a month is a bit much, but it is definitely worth the drive."

Annette Eubanks
Aging Program Director
Mid-East Commission
Area Agency on Aging

[Talking about her inconvenient distance from the November and December meeting site]

"It seems that there is consensus among work group participants that significant changes are needed. What may be needed (once we can better articulate what changes we would like to see) is information about how we can best realize our vision for change for individuals in our state. How can we impact the legislature, create laws, oversight, etc. to protect seniors and those with disabilities so their rights are not taken away?"
—Anonymous Workgroup member

"I think this has been a most effective task force with all the right people" —Anonymous Workgroup member

“Identify target areas to focus efforts of group. What do we do next?”

—Anonymous Workgroup member

“You've done fine so far, have my trust; [we] NEED MORE STORIES - they lead to attitude adjustment which lead to education, to openness, to change—which can increase independence and dignity”

--Anonymous Workgroup member and family advocate

What has been most useful, productive, or effective about this workgroup in its first year?

“Time to interact with stakeholders to find common ground”

“The difficult perspectives that each member of the group brings”

“Bringing together all areas that are impacted by guardianship”

“Having such a wide and diverse group of interests in one room and hearing different perspectives”

“I love the composition of the group, the culture of the group and the facilitators are wonderful”

--Five anonymous Workgroup members

giving the top answer of 5 and another 4 (20%) answering 4. (Of the remaining 20%, 15% answered 3, and 1 person –5%– answered 2.

The other rating question asked, “To what extent do you believe the time you have spent on this task force has been a good use of your time?” with the same scale of 1=very poor use and 5=very good use. The mean answer for this question was 4.2 with a median of 4. This translates into 8 people (40%) each rating 4 and 5 and the remaining 4 people rating 3.

To the request, “Please give us any suggestions you have for course-corrections that you think would make this work group more effective,” we received 21 ideas from 17 people. The three predominant themes—with four people expressing each—were:

- Anxiousness to solidify plans and identify actions;
- The need for more information on how to bring about the needed change most effectively; and
- Praise for the workgroup and confidence that we are on course, including two who praised the diversity of participants.

To the question, “What would you like to see more focus on as we move forward?” we received 21 distinct and specific suggestions which the workgroup will use in helping to set the common agenda. Examples include:

- Collecting more stories from self-advocates and family advocates;
- Obtaining more information about supported decision making and other alternatives and discussing how they can apply to each of the different communities we serve; and
- The need for training on a variety of guardianship topics to a number of different audiences from self-advocates to legislators.

To the question, “What has been most useful, productive, or effective about this workgroup in its first year?” people cited specific data, presentations, or ideas that they had found useful but 15 of the 20 respondents (75%) included in their statements the value of sharing information with such a widely diverse group of stakeholders and learning from people whose perspectives and experiences were different from their own.

As these stakeholders reported, the participants represent a diverse group. Looking only at those who have attended at least two of the five meetings, the following sectors have been represented, in most cases by multiple organizations, agencies, divisions, or companies:

- Self- and family-advocates (3 family and one self-advocate)
- Government — state (6) , regional (1), and local (2)— representing aging, social services, IDD, mental health and substance abuse, department of justice, and the conference of county clerks.
- Nonprofits (4), including First in Families of North Carolina, serving and/or advocating for various combinations of older adults, people with intellectual and developmental disabilities, people with traumatic brain injury, and people with other disabilities
- Businesses (4) — two serving seniors, one serving anyone needing guardianship of the estate, and one LME-MCO
- Professional Associations (3) — including the NC Bar Association, the National Guardianship Association, and the Post-Secondary Education Alliance (an alliance of advocates for postsecondary education for students with intellectual disabilities).
- University — 1 other than the Jordan institute for families, though others have been invited and some have attended a meeting

At the final meeting of the year, Workgroup members suggested a number of other groups that need to be better represented as well as the need to increase the number of self-advocates and family advocates. Recruitment will continue into the second year of the initiative.

We have begun building a knowledge base of best practices in guardianship and its alternatives

The initiative was fortunate to have an MSW student acting as research assistant for this initiative. She led the collection of literature and placed each piece in a folder on the cloud-based file sharing service Dropbox, making it available to everyone participating in the Rethinking Guardianship Workgroup.

Currently the electronic file contains 85 resources related to scholarly studies and data, national reform efforts, least restrictive alternatives, person-centered planning, supported

decision making, and best practices. In addition, she prepared a searchable, annotated bibliography of the contents so members can easily identify documents of most interest to them; this is also saved on Dropbox.

This assistant was also our primary liaison with the WINGS initiatives. She attended the March 11, 2015 Steering Committee meeting of the Utah WINGS program. In addition, she held the following discussions with WINGS staff members in other states.

- Karolina Abuzyarova, Utah WINGS — discussed the theory and practice of multi-disciplinary evaluations and the Guardian ad Litem role.
- Erica Wood, the Assistant Director of the American Bar Association Commission on Law and Aging — answered questions about data collection decisions and procedures in established WINGS states. Wood revealed that the majority of WINGS states are still in a preliminary phase of planning shared measurement.
- The Texas WINGS provided the most current demographic data. Discussion topics included the use of court visitors and investigators as a critical function, the benefits of case management systems, and the need to improve communication with families—especially in the public complaint process.
- New York WINGS provided success stories and described the pressing issues of The Guardianship Project of the Vera Institute of Justice.
- Mississippi WINGS held their first full committee meeting in September, and are planning to collect data, promising to update the NC workgroup when methods are determined.
- Ben Ashley-Wurtmann, Policy and Outreach Associate, Minnesota WINGS, expressed interest in collaboration with the North Carolina Workgroup and discussed the challenges of developing improved data collection.
- Washington DC WINGS discussed their primary data difficulty—that the system maintains the number of guardianship cases filed each year in the court’s annual public report, which does not distinguish civil proceedings and guardianship.
- Ohio WINGS collects the number of guardianship cases

filed and the number of guardianship cases closed in the probate courts throughout the state. They discussed a survey that they will do in the upcoming year, with university assistance, but have not yet finalized exactly what is being measured.

- Wisconsin WINGS has established workgroups. One called “Competency of the Individual and Alternatives to Guardianship” will develop materials for families to consider alternatives to guardianship, including Supported Decision-Making.
- Shirley Bondon, a Health and Aging Policy Fellow and Manager at the Office of Guardianship and Elder Services in Washington State, offered information on an upcoming Restoration of Rights project in collaboration with the American Bar Association.
- Washington State WINGS uses a case management system, similar to Minnesota, for data collection. They have created “a groundswell of support: to make guardianship reform a priority.”

In addition to the written materials and discussion with existing WINGS states, group meetings have included presentations on the Collective Impact framework with examples (March, April); WINGS (March, April, November); parallel developments in the Adult Network of Support (July); the range of alternatives to guardianship (October); data from the focus groups and online survey of clerks of superior court and public guardianship data from the Administrative Offices of the Court (November); and measurement ideas and findings from WINGS and related guardianship studies (November). These presentations have drawn on the expertise of workgroup members as well as speakers brought in from outside the group.

We have begun building a collection of relevant data to support innovative approaches to guardianship alternatives

The primary data collection task for the first year of the initiative was to gather information about the guardianship process from the clerks of superior court. After discussion with key informant and workgroup member Meredith Smith from the UNC Institute of Government, the data and evaluation support team chose to supplement the assigned online survey with focus groups to deepen our understanding of the

qualitative data, and to examine the information available from the Administrative Offices of the Court. The survey and focus group questions were driven by the charge given to the team by the Division of Aging and Adult Services and by the issues and problems reported by workgroup members during the first three meetings of the workgroup.

In addition, public data from the Administrative Offices of the Court (VCAP data) were analyzed to provide numbers of hearings and results for the past five state fiscal years. Following are some key issues with implications for future action, with the findings that support them. A description of the methodology employed can be found in Appendix B.

“The lack of education of guardians about what to expect is a weakness of the system.”
—Clerk in a focus group

Families Need More Information—before Filing and after Appointment as Guardians

- More than two-thirds of clerks responding to the survey (68%) reported that “A family member seeking to be the guardian is largely unaware of what the role entails” most of the time.
- In focus groups clerks made 14 comments about how families really did not know what they were getting into—especially as general guardian or guardian of the estate.
- 72% said “yes” they would like to have more resources to share with family guardians and checked, on average, 3 types of resources they would like to have.
 - Preferred resources were booklets (84% of those who wanted resources), one-page fact sheets (84%), and lists of websites and publications (70%).

“I would like for family guardians of the person or the estate to have required training of the responsibilities.”
— Clerk responding to the online survey

Evidence Presented at Incompetency Hearings May Be Inadequate

Background. The standard for declaring an adult incompetent is “clear, cogent, and convincing evidence” (GS 35A, § 35A-1112. Hearing on petition; adjudication order, section. d). It does not require proof beyond a shadow of a doubt. Both the petitioner (person asking for the declaration of incompetence) and the respondent (person whose competence is in question) have the right to “present testimony and documentary evidence, to subpoena witnesses and the production of documents, and to examine and cross-examine witnesses” (§ 35A-1112. Hearing on petition; adjudication order. Section b).

“You can’t get an MDE. There is no one to do it and no one to pay for it. Sometimes when you get them back, you’re just as confused. They can be in technical language, and there are no actual recommendations to guide the decision.”

—Clerk in a focus group

“One thing I do besides relying on the GAL, I order a social evaluation. Ordinarily, DSS fills that in unless they’re the petitioner. The respondents’ history and life experience is in this evaluation so that if suddenly the son wants to make the decisions for Dad, but the evaluation shows the son hasn’t visited for 5 years and the daughter gives him his meds, and knows he wants to watch the *Today Show* every morning, I know what’s going on. Our DSS is wonderful about contacting all of the collateral contacts in a family—especially all the adult children for older adults. I really rely on that part of it. This is in addition to what the GAL does, but usually the GAL’s is not as good. Sometimes I use MDEs—a social assessment is part of the MDE, but if not a full one, at least a social evaluation.”

—Clerk in a focus group

The statute lays out procedures and powers for ordering a multi-disciplinary evaluation (MDE) in which professionals from one or more disciplines provide assessment information on the respondent (person whose competence is in question) and recommendations. However, the clerk is not required to order this evaluation. It also lays out the rights of the respondent to retain council and procedures for appointment and duties of a *guardian ad litem* (GAL) in the absence of council. (In practice, both the respondent’s attorney and the guardian ad litem may appear.) The guardian ad litem is specifically ordered to represent both the respondent’s expressed wishes and may “make recommendations to the clerk concerning the respondent’s best interests if those interests differ from the respondent’s express wishes” (§ 35A-1107. Right to counsel or guardian ad litem, section b).

Findings: For a Variety of Reasons, MDEs Are Not Widely Used

- Slightly more than half of the clerks reported that they used MDEs for fewer than 10% of their incompetency hearings. Only 12% (about 8 clerks) reported that they used MDEs for half or more of their cases. The 53 clerks who ordered MDEs less than 25% of the time indicated their reasons (as many as they wanted):
 - I usually have enough evidence of competence or incompetence without it (56%)
 - The time it takes to receive the MDE (42%)
 - There is no funding stream or budget line to cover the cost (38%)
 - The cost is prohibitive (23%)
 - In addition, 6 clerks (11%) wrote in that they order one when they need it; 4 wrote that local agency providers are either not qualified or do not understand what is needed and 2 wrote that the information they receive is of poor quality or unhelpful
- 65% of clerks do not know how much an MDE for someone in their county costs. Among those who do know, costs range from a few hundred to \$2,000 or more, with 61% reporting less than \$1,000.
 - More rural than urban counties report MDEs costing \$1,000 or more
 - Clerks in counties with high cost MDEs used them less often

- Clerks with more than 10 years' experience use MDEs less often than clerks with less experience.

Findings: Guardians ad Litem (GALs) Are the Most Relied Upon Source of Testimony

"If I didn't trust a GAL I wouldn't appoint them. I put a lot of faith in what they tell me. . . . The GALs see how they react, how they respond to questions in their own setting. They can also see the home surroundings. They tell me if everyone in the family is seeing the same thing or different things—not only for the ruling of incompetence but for the decisions about the guardian—whether or not the parents/family members are able and willing to take care of the ward for the rest of their lives."

—Clerk in a focus group

- 90% of clerks rate testimony of the GAL as "very important," and 31% say that the GAL's testimony is the single most important source of information—more than any other type of testimony. (MDEs, when available, were the second most important, chosen by 27%.)
- Asked to report the frequency of a set of scenarios as "rarely or never," "sometimes" or "most of the time," nearly all clerks (96%) report that the GAL has met with the respondent before the hearing and made a reasonably thorough assessment "most of the time."
- Not quite two-thirds (62%) also say that the GAL has tried to identify a family member to serve as guardian "most of the time."

Nearly all (97%) of the clerks agreed (51%) or strongly disagreed (46%) with the statement "I almost always strongly consider the GAL's testimony about the family before appointing a family guardian."

"I require [reports from private guardians], because we've had someone that came in and got 'guardian of the person' but the guardian left the person here and moved back to New York. So now I require them to come in and file the report so I have some way to know what's going on. I'm still trying to get up with the person in New York, she just left."

—Clerk in a focus group

Monitoring of Private Guardianship of the Person Is Not Mandated

Background: There is accountability, by law, for guardians of the estate or general guardians because they handle money. They have to file an annual account of all transactions.

Public guardians of the person (DSS or corporate through contracts with DSS) must make a report 6 months after appointment and annually thereafter.

Reporting for private guardians of the person is entirely at the discretion of the court. As the following chart shows, only a quarter of clerks routinely require such follow-up.

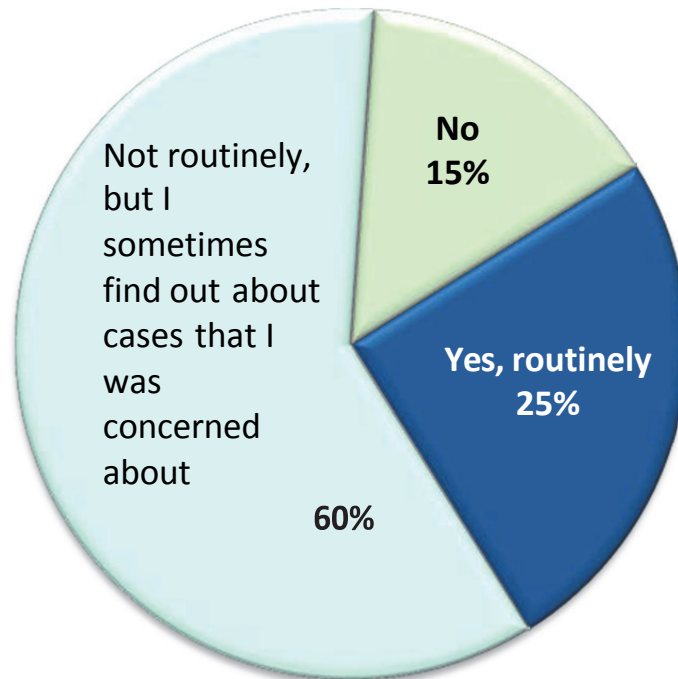
Findings: Evidence from Petitioners and Respondents Is Not Highly Valued

“We also see a lot of petitioners who do not have a clue about how to gather or present evidence. I’ve also had agencies not give any evidence. They just say he needs guardianship.”

—Clerk in a focus group

- Half of the clerks reported that the petitioner has not gathered any supporting evidence for a claim of incompetence “sometimes”; another 16% indicated this occurs “most of the time.”
- While 73% of clerks said that the testimony of the petitioner is “very important” in making their decision, only 48% gave that rating to the testimony of the respondent/ward, and 45% to the testimony of family and friends of the respondent.
- Similarly, only three percent said that the testimony of the petitioner was the most important source of information and one percent said that the testimony of the ward (when available) was the most important source.

Assuming that there is not a petition to replace a family guardian; do you receive any information about how family guardianships work out?



A Person Adjudicated Incompetent Can Have Competency Restored, but This Rarely Happens

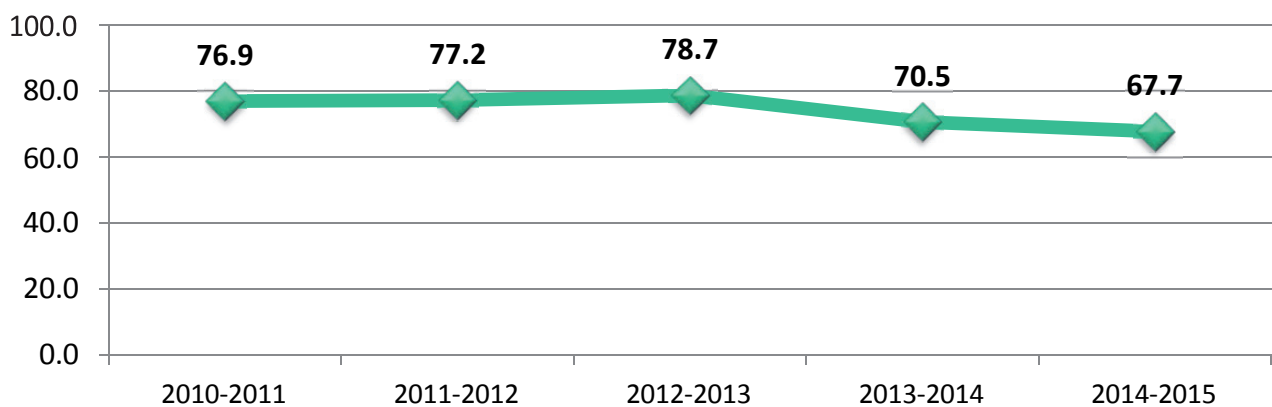
A ward, a guardian, or another interested person can file for restoration of competency.

In each of the past five state fiscal years, 40 or fewer of the 100 counties had any restoration hearings.

Source: Abstracted by the initiative data team from Administrative Offices of the Court public data.

- In state fiscal year 2014-15, there were only 130 hearings for restoration to competency in the state. If we assume the conservative estimate of 15,690 wards, this is 8 per 1,000 seeking restoration. Of these 88 were granted (two thirds).
- This low number still represents a sharp rise from an average of 86 cases per year in state years 2011 to 2013 to 112 in 2014 and 130 in 2015.
- As the number of hearings increased, the percentage of hearings ending in restoration of rights declined slightly, as shown in the following graph. Advocates endorsed speculation that this might reflect a greater willingness for wards and/or their guardians to file for restoration without necessarily believing they had an irrefutable case.
- Although advocacy for restoration has been encouraged in the Intellectual and Developmental Disability community, clerks report that the few restorations on which they have ruled have involved people recovering from accident or illness, substance abuse, or mental health issues.

Percent of Restoration Petitions Granted in Whole or in Part



A Rare Problem Is Still a Problem to the Person to Whom it Happens

When asked the frequency of some problems reported by advocates, clerks chose “rarely or never” for some situations and “sometime” for others. However, even those problems for which most clerks chose “rarely or never,” were significant to clerks who reported they “sometimes” happen and the people they happened to. Although these are clearly not widespread problems in the system, there is a need to discover the circumstances in which they happen and how to avoid them. The following table shows the problems in question.

Scenario	Percent of Clerks		
	Rarely or Never	Sometimes	Most of the Time
The Guardian ad Litem has met with the respondent for the first time at the Courthouse on the day of the hearing.	88	11	1
A hospital or residential facility is filing or has suggested that the family file because the facility or family believes guardianship will provide financial resources for the ward's care.	53	41	6
Guardianship is sought because of family disagreements that might have been settled through mediation.	51	46	2
A hospital or residential facility is filing or has suggested that the family file because they have no good discharge options.	33	60	7
A petition is filed for guardianship when the situation could have been handled through other means (e.g., power of attorney, representative payee, support team).	30	57	12

We have begun to identify changes needed

Group exercises during the five meetings to date have stimulated discussion across sectors on the services and supports needed by people who may experience guardianship, and what constitutes a high quality of life in that context (April), strengths and weaknesses of the NC Guardianship system (July), and how to develop county-level pilot initiatives with a common agenda (July). Nearly every meeting has included some discussion of problems that need to be addressed, as reflected in the issues addressed by data. The December meeting will help members move toward identification of a set of recommendations.

Modeling the five elements of Collective Impact in the workgroup

Besides teaching about the Collective Impact framework at every meeting, the team at the Jordan Institute for Families has tried to model the five elements in their activities with the workgroup.

Backbone infrastructure was modeled in the team's service to the workgroup. Our goal was to provide the supportive structure for the group to make its decisions—not to govern or lead, except by example.

Continuous communication was modeled by emails before and after meetings as well as the face-to-face meetings themselves. Members were notified when new materials were placed in Dropbox and encouraged to share their own materials and resources with the entire group. Frequent updates were given on research progress even before findings were available.

Discussion began on a **Common Agenda** at the very first meeting. Although all are committed to improving guardianship in general and promoting alternatives whenever possible, a more specific focus for action has not yet crystalized.

Mutually Reinforcing Activities cannot be decided on until the common agenda is in place. However, there is substantial consensus that one of the elements will be the education of families, self-advocates, the courts, and other groups about alternatives to guardianship. Another idea with widespread support is modifying GS 35A to allow clerks to recognize a supported decision making team as an alternative to declaring incompetence and appointing a guardian.

Shared Measurement is another element that cannot be put in place until mutually reinforcing activities are identified. However, the sharing of available data about the context of the problem as well as data from other states has helped to focus group attention on this issue. As we have learned, in conversation with members of WINGS groups in other states, it is one element that also challenges most of them.

Moving to State and Local Action—Year Two

Local Level

Working in conjunction with the Adult Network of Support collective impact initiative, which has representation from the Rethinking Guardianship Workgroup and the NCCDD, team

members helped to draft a Request for Information (RFI) that will go out in December, calling for local pilots in either the area of guardianship, or in Alzheimer's support (with Adult Protective Services implications). Through this or a parallel process, the workgroup will identify and support one or two local initiatives.

A sub-committee of the workgroup will coordinate with the local Collective Impact pilot(s) to ensure there is substantial alignment between the agenda and mutually reinforcing activities of the local and state groups. However, local control of their pilot is essential to the Collective Impact framework. Although the local pilot must develop its own backbone infrastructure, the committee will assist with early backbone functions including:

- Educating the local collaborative about the Collective Impact process and the issues of guardianship the state workgroup has identified;
- Helping to secure funding to support the local entity performing the backbone function; and
- Assisting with data collection both to help understand local context and to complete the pilot self-evaluation.

State Level

At the state level, the workgroup data team will analyze the individual level data they have received from the Administrative Offices of the Court. This will allow them to look at longitudinal patterns in both changes in guardianship and the average time that people who seek restoration spend in guardianship. This will also allow us to make more informed recommendations for modifications in the VCAP system.

The workgroup will continue using the Collective Impact framework to finalize a common agenda and choose the most important mutually reinforcing activities represented government, nonprofits, businesses, professional associations and advocates can undertake. Thus, they will not just make recommendations but, in line with WINGS guidelines, can begin the process of making state-level reforms through advocacy for changes to policy, practice, and statute and, in some cases, shifting the focus of activities in their own spheres of influence.

Conclusion

In the course of this first, formative year, this initiative has:

- Put together a diverse and committed workgroup.
- Learned about and adopted the Collective Impact framework for addressing complex problems and the WINGS initiative that is applying this framework in other states.
- Educated itself on guardianship issues from previous workgroups, published literature, and the life experiences of advocates and other group participants.
- Collected and analyzed information from the clerks of superior court who are the judges in guardianship cases.
- Analyzed published data from the Administrative Offices of the Court and obtained identified data that will permit longitudinal analysis in the coming year.
- Made good progress in the developmental stage of the Collective Impact process and laid the groundwork for the formative stage in the coming year.

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Appendix A. Recommendations from Earlier Guardianship Initiatives

This appendix contains findings, recommendations, and summary information from three different reports on guardianship: The Public Guardianship Ad-Hoc Workgroup Report, The Final Report from the Subcommittee on Public Guardianship, and the Final Report on the Examination of Ways to Improve the Public Guardianship System. For the full text of the reports please use the bibliography information to locate the full reports.

Public Guardianship Ad-Hoc Workgroup Report (December 2013)

Findings:

- 1) NC's model of public guardianship, which positions the disinterested public agent guardian as the guardian of last report, does not cap the number of guardians available to the public, utilizes a mix of private corporations, public social services, and local clerks of court, is good public policy and serves people most in need of a legal surrogate decision maker.
- 2) Private corporations fulfill a vital role in NC's system of public guardianship.
- 3) People being served by a public guardian have complex needs, few resources of their own, and will likely need a guardian for many years.
- 4) Guardians generally, and public guardians specifically, experience difficulty accessing the array of mental health services provided by LME/MCOs on behalf of the people they serve.
- 5) The vast majority of NC's public guardianship service is supported by federal and county funds (96%); the state contributes only 4%.
- 6) The number of people needing a public guardian will continue to increase.
- 7) Current and future demands for a public guardian cannot be met without additional resources, primarily in the form of additional funding.
- 8) A public guardian is being appointed on average 30% of the time when a guardian is needed.
- 9) Pursuant to NC G.S. 35A, a guardian of the person is not entitled to receive a fee for their services and time spent carrying out their duties. They are only entitled to receive reimbursement of reasonable expenses incurred.
- 10) DSS directors experience a number of conflicts of interest fulfilling their role as the sole public agency serving as guardian. These conflicts include, but are not limited to, the conflict of interest when serving as guardian for an adult with child(ren) in custody of the DSS.

Recommendations:

- 1) Maintain NC's public guardian model utilizing county departments of social services and corporations, when publicly funded.
- 2) Provide adequate resources for the current and future needs of NC's public guardianship service, including:
 - a. Adequate state funding of \$2.5 million to add 33 FTEs statewide (33 Social Work III positions @ \$75,000) in order to meet the recommended 1 FTE : 22 wards caseload standard
 - b. Restore funding so corporations that receive public funds to serve as guardians can be reimbursed at original funding levels (\$213.17/ward/month)

- c. Provide funding to expand the capacity for existing corporations and increase the overall number of corporations available to serve as public guardians
- 3) Implement statewide, standardized procedures to ensure that a public guardian is appointed only when no other appropriate individual is available and able to serve:
 - a. Statutorily require that a guardianship assessment be completed prior to an appointment hearing before the clerk of court on the adjudication of incompetency and appointment of a guardian when there is a likelihood that a publicly funded guardian will be appointed
 - i. Demonstrate the need for and efficacy of this requirement by implementing a statewide pilot for a 12 month period to allow for 1,328 assessments to be completed. A pilot will provide the opportunity to evaluate savings to the public guardian system, demonstrate the benefit of a collaborative system for the incompetent adults, reduce overall liability and exposure of the public system, and improve the appointment process.
 - b. Provide \$337,500 in State funding to complete up to 1,328 assessments by county DSS staff for a pilot year
 - c. Modify NC G.S. 35A-1202(14) and 1242 to statutorily require the public guardian's efforts to restore competency, seek alternatives to public guardianship, and make recommendations to limit guardianship be included in status reports and submitted to the clerk for review.
- 4) Improve access to the array of service provided by LME/MCOs to meet the needs of adults with severe and persistent mental illness, intellectual and developmental disabilities, and substance abuse. The NC Division of Mental Health/Developmental Disabilities/Substance Abuse Services will convene a workgroup to:
 - a. Explore the overlapping population of adults in need of court-ordered guardianship between court-appointment guardians (including DSS, corporations, and individuals) and the population accessing behavioral health services at LME/MCOs
 - b. Examine barriers to services and make recommendations to address them for the adults and their families
- 5) Address the conflict of interest in situations when the DSS director is serving as guardian for an adult who has child(ren) in DSS custody.
 - a. Identify public funding to pay for appointment of a corporation, another DSS, or a private individual to serve as guardian in instances where this conflict of interest exists
 - b. Study further to identify all types of conflict of interest encountered by public guardians and develop recommendations to address these conflicts
- 6) Study and make recommendations for improvements to strengthen NC's public guardianship system including:
 - a. Review and improve state laws governing medical decision making to ensure that guardians are only appointed when necessary
 - i. Collaborate with the NC Bar Association, Elder Law Section, and other stakeholders to consider revisions to NC G.S. 90-21.13 to clarify the role of surrogate decision makers in health care settings
 - b. Review appropriateness and effectiveness of utilizing a publicly-funded guardian for incarcerated adults

- i. Collaborate with the Department of Corrections, clerks, and other stakeholders with interest to clarify the role, purpose, and cost-effectiveness of a publicly funded guardian for incarcerated adults
- c. Study the potential imposition of a fee for guardianship services of the person in addition to currently allowable reimbursement for expenses
 - i. Consider revision to NC G.S. 35A to require the ward's resources be used to pay a fee for guardianship services whenever possible
 - ii. Consider whether public guardians could charge a fee for services in the event a private guardian is unavailable or too expensive given the ward's resources
 - iii. Develop a network of adult individuals and private corporations who could be paid a standard fee for service as guardian of the person
 - iv. Develop a standardized fee structure to be imposed by guardians of the person in carrying out their duties
 - 1. Reference Illinois Statute 755 ILCS/Sec. 27-1. *Fees of representatives* as an example of allowable fees and schedule
 - v. Study the current level of legal support provided for guardianship within county departments of social services and make funding recommendations for additional legal support as needed

Final Report, Subcommittee on Public Guardianship (March 11, 2014)

Findings

This report explicitly affirmed the 10 findings listed in the Ad-Hoc committee's report. Additionally, it reported the following findings:

- 1) Further study of public guardianship is needed, including allowing the subcommittee to continue its work of exploring and examining all of the issues and information affecting the provision of guardianship services.
- 2) Greater oversight is needed of public guardians of the person and public guardians in general. It is important that more detailed information regarding the ward be available for review by the clerk.
- 3) Individuals served by a publicly-funded guardian generally are vulnerable individuals with complex needs. In many cases, guardians can be supportive and serve to maximize a ward's potential and quality of life. It was reported to the Subcommittee that there may have been cases in which public guardians have been non-responsive, impeded employment and housing opportunities, and obstructed appropriate restoration of competency or modification of guardianship. In cases where the clerk or the DSS receives a report of abuse, neglect, or exploitation of a ward, it is important that appropriate protection and advocacy services be provided. The ward should be offered an opportunity to provide information to an investigator and to participate as fully as possible in all decisions that affect him or her. The DSS should have specific protocols and policies to govern guardians, including responsiveness, personal contact with the ward, and a person-centered plan, and should develop plans for each guardian in order to ensure that the ward's needs are met and that the guardianship plan is regularly monitored.

- 4) Changes to State guardianship laws made as a result of the 1915(b)/(c) Medicaid Waiver limit the clerk of superior court when appointing a disinterested public agent as guardian to the appointment only of the director or assistant director of a county department of social services. Clerks of superior court no longer have the authority to appoint an area mental health agency or other human services agency as a disinterested public agent. National Guardianship Association standards provide that the guardian shall avoid all conflicts of interest and self-dealing, or the appearance of such, when addressing the needs of the person under guardianship. Such conflicts may be based on moral, ethical, and/or financial reasons and can arise, for example, when the guardian directly provides housing, medical, legal, or other direct services to the ward and is not a family guardian approved by the court to provide specified direct services that are in the best interest of the ward. Guardians should be educated as to what constitutes a conflict of interest and self-dealing and why they should be avoided. Under current State law, if a disinterested public agent believes that his role or the role of his agency in relation to the ward is such that his service as guardian would constitute a conflict of interest, or if he knows of any other reason that his service as guardian may not be in the ward's best interest, the disinterested public agent is required to bring such matter to the attention of the clerk and seek the appointment of a different guardian. Virtually all presenters who addressed the issue of parents and relatives as both guardians and paid service providers agreed that the clerk of superior court should continue to have the discretion, based on full information and a determination as to the ward's best interest, to appoint the person who will take the best care of the ward.
- 5) The Subcommittee heard from presenters that the potential for a conflict of interest arises when a county department of social services has been appointed as guardian for both a child who is the subject of a report of abuse, neglect, or dependency that must be investigated by Child Protective Services as well as for the parent or legal guardian of that child.
- 6) Although it is unusual for individuals requiring public guardianship services to have significant financial resources, there are wards whose guardians are individuals, corporations, or disinterested public agents who have assets to be safeguarded and whose financial affairs must be properly managed. Many wards may be receiving Social Security, SSI, or other disability benefits. The Subcommittee was informed that there is a potential conflict of interest as well as opportunity for abuse and exploitation when a guardian seeks to be designated as representative payee of the ward's Social Security or SSI benefits or is the payee of other public monies. The issues relating to these financial conflicts of interest warrant further examination and study.
- 7) Clerks, through their judicial role, make a determination as to who is best able to act in the best interest of a ward. Clerks use a variety of means by which to gather information to assist them with this decision, including conducting criminal background checks, conducting interviews, reviewing medical records, and examining family dynamics. Clerks need to continue to be allowed discretion to make those decisions appropriately and based on full information, in order to choose whomever they believe is going to take the best care of the ward. Clerks are currently working with their local departments of social services to ensure that all private guardianship possibilities are exhausted before appointing a public guardian. A guardian has tremendous power and authority, whether compensated or not. There is a need to focus on the interplay between the personal decision-making responsibilities of a ward who receives a great number of public service dollars. As a practical matter, any amount of compensation a guardian receives for providing guardianship services is significantly less than the amount of dollars that may be needed

for the ward on the service side. In some jurisdictions, there may be a trend to disallow a guardian who is making decisions as to what services are needed and appropriate for the ward to also be a paid provider of those services. Recent case law in the State stands for the proposition that it is not in the best interests of the ward and that there exists an actual or potential conflict of interest when an entity is both providing services and acting as guardian. On the other hand, there was consensus among the presenters that no one can better serve as guardian than a family member who cares about the ward and has perhaps spent a great deal of his or her life providing for the ward's care. The presenters agreed that not only is any movement towards appointing disinterested third parties and away from private individuals as guardians concerning, but also in some situations where a parent or relative cannot work outside the home because of the needs of their ward, it may be in the ward's best interest for that parent or relative to serve both as the guardian and a paid provider of services. In fact, in situations where, because of the nature of the ward's disability, they need full-time, around-the-clock care, it might be in the ward's best interest for the parent to be a guardian who receives a monthly stipend as well as a paid service provider, and it might be less expensive for the State. Conflicts of interest are more likely to arise where money is changing hands and there is no familial or moral obligation towards the ward on the part of the guardian. Clerks, through their judicial role, are charged with the legal responsibility of making a determination as to what is in the best interests of the ward, and thereby need discretion to choose whomever they believe is going to be the best person to serve as guardian and to act in the best interest of ward. Parents and other relatives, as permitted under current law, should continue to be both guardians and paid providers when appropriate, if adequate oversight is present. However, a plan should be in place for an alternate guardianship arrangement in the event an individual guardian of the person becomes unwilling or unable to serve, and such plan should explore all possible alternatives to prevent the appointment of a public guardian in order to ensure the best interests of the ward as well as to safeguard the resources of the State. In addition, a plan should be in place for provision of services by an alternative provider.

Recommendations

- 1) Appoint a subcommittee on public guardianship for the 2014-15 interim.
- 2) Support the enactment of legislation (2013-SHz-9) by the General Assembly to amend the requirements contained in the provisions of the General Statutes relating to the contents of status reports that must be filed by guardians with the clerk of superior court.

The Subcommittee on Public Guardianship, Joint Legislative Oversight Committee on Health and Human Services, recommends the Joint Legislative Oversight Committee direct:

- 3) The Division of Aging and Adult Services (DAAS), Department of Health and Human Services, to collaborate with the Administrative Office of the Courts to develop a plan regarding the evaluation of complaints by DAAS so that, in addition to current requirements, the complaint process also incorporates a face-to-face observation of the ward and/or an interview with the ward. The plan shall provide that the interview or observation be performed by an individual who is experienced in understanding the unique needs and abilities of the ward.
- 4) A subcommittee study the issue relating to potential conflicts of interest between public guardians, wards, and services providers, and that the subcommittee report its findings and recommendations.

- 5) The Department of Health and Human Services, specifically the Division of Social Services, to study the issue of conflicts of interest in child welfare cases, and to make recommendations in a report to the Joint Legislative Oversight Committee. Among the various options to be considered in order to address potential conflicts of interest are creating internal firewalls to prevent information sharing and influence among staff members involved with the conflicting cases; creating a formal or informal "buddy system" allowing a county with a conflict to refer a case to a neighboring county; referring the guardianship to a corporate guardian until the child welfare case is resolved; having the Department of Health and Human Services assume responsibility for either the guardianship or the child welfare case; and legislation to permit the clerk the option of appointing a public agency or official other than the director of social services to serve as a disinterested public agent in exceptional circumstances.
- 6) A study of the issues relating to potential conflicts of interest when funds are involved and a guardian is designated as representative payee. The Joint Legislative Oversight Committee may direct a subcommittee to study the issues or direct a particular agency or agencies to study it and report findings and recommendations.
- 7)
 - a. The Department of Health and Human Services continue utilizing safeguards already in place regarding guardians as paid service providers, and that the Joint Legislative Oversight Committee direct the Division of Aging and Adult Services and/or the Division of Social Services to consult with the clerks of superior court, the LME/MCOs, the North Carolina Bar Association Section on Elder Law, and any other interested groups, to develop a transition plan for when a parent/caregiver is no longer able to provide care or be a guardian, with the specific goal of formulating a plan that will avoid the necessity of making an individual a ward of the State, and to report its findings and recommendations to the Joint Legislative Oversight Committee.
 - b. The Department of Health and Human Services to continue to study whether utilization of care coordination services would provide needed oversight to safeguard against conflicts of interest when guardians serve as paid providers.

Final Report on the Examination of Ways to Improve the Public Guardianship System (October 1, 2014)

Session Law 2014-100, Section 12D.3 requires the Department of Health and Human Services, Division of Aging and Adult Services (DAAS) to examine ways to improve the public guardianship system and submit a report of its findings and recommendations for each of the areas examined. The two plans contained in the report incorporate stakeholder participation and recommendations for improving the public guardianship system.

Specifically, Section 12D.3.(a) requires DAAS to collaborate with the Administrative Office of the Courts to develop a plan to evaluate complaints pertaining to wards under the care of publicly funded guardians. Section 12D.3.(b) requires DAAS to collaborate with stakeholders to develop a model plan for transitioning wards to alternative guardianship arrangements when an individual guardian of the person becomes unable or unwilling to serve. Section 12D.3.(c) directs DHHS to continue to study whether utilization of care coordination services would provide needed oversight to safeguard against conflicts of interest when guardians serve as paid providers.

This final report is divided into three sections. Section I is the Plan for Evaluating Complaints Regarding the Performance of Guardianship Duties by Publicly Funded Guardians. This plan describes the procedures DAAS currently follows to evaluate complaints and now includes the new requirement to conduct an observation and/or face-to-face interview with the ward.

Section II is the Model Plan for Transitioning Wards to Alternative Guardianship Arrangements. This plan describes the components of the model plan, including strategies for implementation and possible legislative changes.

Section III is the Study of Oversight for Guardians as Paid Providers. This section lays out how DHHS is continuing to examine whether utilization of care coordination services would provide needed oversight to safeguard against conflicts of interest when guardians serve as paid providers. The Department, through its Division of Medical Assistance and Division of Mental Health, Developmental Disabilities and Substance Abuse Services, is soliciting input from a variety of stakeholders on the important issue of Guardian as provider. We anticipate having our recommendations by January 2015.

Appendix B. Research Methodology

The research for this initiative has taken part in three distinct pieces: focus group-like sessions with the clerks of superior court, an online survey with the clerks of superior court, and analysis of data from the Civil Case Processing System (VCAP) which is maintained by the Administrative Office of the Courts (AOC).

The focus group-like sessions were held on Wednesday, August 19, 2015 at the summer conference for clerks of superior court. At the sessions, we used the “Focus Group Protocol” (Appendix C), though these sessions were too large to be true focus groups. One team member led the discussion while two took detailed notes (as close to verbatim as possible) and one took more general notes.

The focus group-like sessions generated a considerable amount of qualitative data. Additional qualitative data came from notes from individuals who talked with one of the team at our booth at the summer conference and the answers to the final open-ended question on the survey. Each pair of session notes was compared and where notes slightly differed, they were grouped as a. and b. versions of the same point. One member of the team generated a list of codes after reading through the material. All three team members coded independently at the level of whole statements by individual speakers (multiple codes allowed per statement). All of the three were permitted to add new codes during this process. Then, statements were divided into those with code agreement and those with some disagreement. The three team members met on the latter group and resolved differences. However, despite formal coding, the qualitative material has been used, to date, primarily to illustrate and provide context for the quantitative findings.

The online survey was designed by the UNC research team, led by Mary Anne Salmon, Ph.D. The survey was delivered using Qualtrics software and was broken into sections that asked about the clerks’ experience with: petitions and preparation, the incompetency hearing, making a ruling on competency, activities after the hearing, and some demographic information. All survey responses were anonymous, and the surveys were sent to the 100 clerks of superior court. 75 clerks completed the majority of the survey questions, resulting in a very high (75%) response rate.

The raw data from the survey was downloaded into Statistical Analysis Software (SAS) where statistical analysis of the data was run. The majority of the analysis is descriptive in nature: showing the percent of clerks who agreed or disagreed with specific statements as well as cross tabs of answers to see if they varied based on demographic factors such as the rurality of the county the clerk came from, or the number of years of experience the clerk had.

The AOC data used is publicly available VCAP data. Some of the data was pulled from pre-prepared reports on the AOC website which could be downloaded as Excel files. An additional data request was made through DAAS for publicly available data which was not in the pre-made reports. We consulted with the AOC data department for guidance on interpreting codes and clarifying what information was or was not represented in the data. The additional data request came with data ID numbers allowing for limited linkages for specific cases—and, thus, some longitudinal analysis. This data has been received very recently and so the cleaning, conversion, and analysis processes have just begun. We have no data to report from this data set yet, but expect to have results soon.

Appendix C - Focus Group Protocol for Clerks of Superior Court

Interview Guide

Facilitators do not need to use this word-for-word as a script, but they do need to touch on each of the points listed as major headings. Questions should be asked *verbatim*, but the facilitator should use additional probes only as necessary to clarify answers or guide discussion. *It is not necessary to use all probes.* Use them to prompt responses to issues that have not come up spontaneously. Try not to give any feedback, or reinforce, summarize or reflect back to them as you would normally do in the facilitation process. So that participants will not perceive your neutrality as cold, you may mention that to avoid bias sharing, you will try not to give any positive or negative responses.

Welcome & Introduction

- Introduce self and note taker.
- Ask people to silence cell phones.
- Before we get started I'm going to give you a brief overview of the *Rethinking Guardianship Collective Impact Initiative Workgroup*, today's focus group, and your rights as participants in research conducted by UNC.

Purpose of the Initiative

To examine whether or not there is a need for long-term changes in North Carolina's guardianship system; to promote less restrictive alternatives to guardianship; and create and implement pilot Collective Impact initiatives around issues of Guardianship in two NC counties.

Purpose of the Focus Group

The purpose of these focus groups is to learn from your experiences in declaring incompetency and appointing both private and public guardianship. Although this initiative is being led by the Division of Aging and Adult Services, our stakeholders represent the full range of the aging and disability communities and we are interested in your experiences with respondents/wards of all adult ages. The goal for today's focus group is to gain deeper insights into the "how" and "why" of these issues that survey surveys alone cannot provide, which will be shared with the *Rethinking Guardianship Collective Impact Initiative Workgroup* and in our final report to the Division of Aging and Adult Services.

Informed consent and confidentiality

As part of the University we need to tell you about your rights as a research subject. You have a handout called Fact Sheet and Statement of Participants' Rights that also covers these rights. Your participation in this focus group is voluntary. You are free to leave without consequence and you are also free to stay but not participate. We are interested in what you have to say, but you must be the judge of what you are comfortable talking about, so I want to reassure you that it is all right if you don't want to share your views on any particular question. You also received a brief survey about your county and your background and tenure as a clerk. We hope you will fill it out to help us better describe our participants as a group, but that is also completely optional as described on the fact sheet.

None of our writing about this initiative will quote anything said here in a way that can be directly connected to the individual who said it. We will also ask you to respect each other's privacy; but, of course we cannot guarantee the discretion of your fellow participants. Further, we remind you to be protective of the confidentiality of the people who have come before you. If you give examples from individual cases, which will be helpful, we encourage you to change the names and alter any identifying details.

There will be no negative consequences for not participating in the focus group, and there will be no rewards for participating except for opportunity to help shape the work of the *Rethinking Guardianship Collective Impact Initiative Workgroup*. Before we begin, does anyone have any questions?

Focus Group Questions

1. The overall purpose of this initiative is to explore and promote alternatives to guardianship that are less restrictive before cases ever come to you. What alternatives to guardianship are you aware of that you would like to see used more often, and what would it take to make that happen? (**Probes:** For example, would there need to be changes in community resources, public awareness/training, n policies, procedures, or laws? Which cases that you see are best or least suited for potential alternatives?)
2. What, if any, abuses or misuses of the guardianship system do you see occurring? (**Probes:** Are there changes you would like to see in laws, policies, standard procedures, or resources for families that could alleviate these issues? If a misuse pertains to misinformation or lack of education about guardianship, what advice should petitioners be given prior to petitioning for guardianship?)
3. In what ways does the current guardianship process provide you with, or fail to provide you with, as much information as you would like to make competency decisions? (**Probes:** What types of cases do you wish you had more information on to make competency decisions? How often does this happen? What changes could be made to get you that information? What options and/or tools are available when you need more evidence?)
4. Generally speaking, what are the strengths and weaknesses of the various entities involved in guardianship proceedings in your county? I'm speaking of the Guardian ad Litem, the county DSS (as petitioner, witness, or public guardian), and other public petitioners, or other participants that you may see in your hearings. (**Probes:** What respondent/ward needs do you see that are not being served or are being served very well? Are there things you wish you could change about your relationships with any of these entities? What do you appreciate about any of these entities?)
5. (Optional, based on time) Tell us a little about your experience with restoration of rights? (**Probe:** How often does this come up? What is or what is not working in this process in your county?)
6. Thank you for sharing your thoughts with us. We are getting ready to wrap up in a few minutes. Do you have any other comments? Are there other questions I should have asked but didn't?

I'll be around for a little while as we adjourn. If there is anything you didn't get a chance to tell me in the group, I would be glad to hear from you. You can also talk to _____ [assistant] who has been taking notes for us. We have a booth set up in the exhibitor's hall which we encourage you to stop by and share additional thoughts and take the brief online survey we have about alternatives to guardianship.

Spontaneous thank yous and goodbyes.

Rethinking Guardianship Workgroup

Julie Bailey, *Parent Advocate,
Mental Health America of the Triangle (retired)*

Lynne Berry, *NC Division of Aging and Adult Services*

Erica Bing, *Alliance Behavioral Health*

Diane Brady, *Legal Aid of North Carolina*

Bill Donohue, *Parent Advocate,
Special Children's School (retired)*

Robyn Dorton, *Self Advocate,
Carolina Institute for Developmental Disabilities*

Corye Dunn, *Disability Rights North Carolina*

Ken Edminster,
*NC Division of Mental Health, Developmental
Disabilities, and Substance Abuse Services*

Jean Farmer-Butterfield,
*The Arc of North Carolina, North Carolina General
Assembly*

Kent Flowers,
Craven County Department of Social Services

Damie Jackson-Diop, *North Carolina Families United*

Frank Johns,
Booth Harrington & Johns, Elder Law Firm

Carol Kelly, *A Helping Hand*

Gale Kirk, *National Guardianship Association*

Betsy MacMichael, *First in Families of North Carolina*

Natalie Miller, *North Carolina Bar Association*

Bonnie Nelson, *The Arc of North Carolina (retired)*

Mark O'Donnell,
*NC Division of Mental Health, Developmental
Disabilities, and Substance Abuse Services*

Mark Pegram,
North Carolina Conference of Clerks of Superior Court

Rosalyn Pettyford,
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Jeanette Wilhelm, *Monarch NC*

Deborah Woolard, *Parent Advocate*

Deborah Zuver,
Carolina Institute for Developmental Disabilities