ABSTRACT

AGING GUARDIANS: DECISIONS & TRANSITIONS

by Hannah Claire Thompson

Court-appointed guardians advocate and make decisions in the best interest of individuals unable to do so for themselves. Guardians are often related to the individual for whom they are appointed (the “ward”) and make difficult living arrangement and medical decisions for the present and future. The purpose of this study was to identify aging guardians (age 60 and over) and examine any planning determined for the future of the individual under their care. In-depth, semi-structured interviews were conducted with ten guardians served by an Ohio probate court. Findings were framed around interview questions to highlight the following topics: parent role & guardianship responsibilities, future transitions, advice, and transition worries. Recommendations for the county probate court include organizing informal informational sessions with layperson guardians concerning future planning strategies. The knowledge of findings will help facilitate better communication between older adult guardians and professionals.
AGING GUARDIANS: DECISIONS & TRANSITIONS

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Guardians are court-approved persons who provide help with decision-making regarding health care and living arrangements on behalf of individuals deemed “incompetent” by a court (Ohio Revised Code, 2015). Guardians are often family members (such as a parent, sibling, or child) of individuals with developmental disabilities, mental illness, or cognitive impairments. Parents are appointed to the role of guardian when a son or daughter is in need of guardianship services. The parent (or family member) must abide by court rules such as attending hearings and completing annual court reports (Ohio Revised Code, 2015).

Trends show that as parental guardians proceed through the life course, an interesting dynamic appears within guardianship programs. It has been observed that the guardian and their individual (usually their child) both go through the aging process (McGinley, 2016). This brings up questions on the guardian’s planning for the future of their individual’s overall well being through planning of secure living arrangements, future health care needs, and a possible transition to a new guardian when one can no longer take on responsibilities. The court wishes for guardians to have future planning decided, especially if an unexpected guardianship transition would occur.

Because guardians tend to be family members, planning for the individual under guardianship is not careless, as decisions are to be made in the best interest of the ward. There are various factors contributing to a family member’s future planning approach to healthcare, living arrangements, and selecting a new guardian. This research study intended to fill gaps in knowledge about the guardian thought process concerning the future and could possibly inform county court officials about what was important to guardians as they plan for their individual under their care. The research question of this current study was: What are older (age 60 and over) guardians’ plans for the individual under guardianship when they can no longer continue the responsibilities set forth by the county probate court and Ohio Law? The study sought specifically to understand the planning process involved for older guardians when they can no longer execute their responsibilities.

This study addressed two aims:

AIM 1: Identify current older adult guardian roles and responsibilities.

AIM 2: Examine future plans (if any) that the guardian might have for the individual under his or her care. This information may include plans for the next guardian (family or a professional guardian), living arrangements, and wishes for medical care.

Research concerning court guardianship practices conducted through government departments, law schools, and other human service researchers has assessed various aspects of the guardianship process at a state and national level. While previous literature examines national guardianship practices, there is little research concerning perceived guardian experience. Qualitative research studies concerning guardianship are lacking in the literature and review shows no evidence of an older adult guardian-specific (age 60 and older) study. Because older guardians face many difficult decisions throughout the years in this role, the transition to a new guardian would be important for the court system and law professionals to study, yet is not a
topic past literature. More studies targeting guardian feelings and experiences of the guardianship process could inform professionals working with older adult guardians, especially if they happen to be family members to the ward.

Older adult guardians must sooner or later transition the role if their individual will outlive them. It may be difficult for older adults to prepare for this ultimate transition for their individual as end-of-life planning and living arrangements should be in place. If older adult guardians are family members (and especially a parent), special circumstances for the future of their individual (or child) may want to be in place for the best possible quality of life. Addressing and analyzing direct guardian feedback concerning guardianship responsibilities and understanding future planning (if any) for the guardianship, will bring a focus to how guardians actually plan for the individual under their care. This study will help local probate courts to understand how current older guardians prepare for transitions in a ward’s guardianship and what older adult guardians’ wishes are for future care.

Background

An Overview of Guardianship

Guardianship practices originated in Britain, under the doctrine of parens patriae (“parent of the country”) when a person was appointed guardian for an incompetent person’s estate. This concept was later adopted in the United State to include both guardianship of the person (health and living arrangement decisions) and (or) the estate (decisions concerning property and money management) (Boxx & Hammond, 2012). As guardianship practices have evolved in the United States, current themes have emerged from law and social service professionals. Most recently, there has been talk about installing guardian standards and a national code of conduct for all those taking on these responsibilities. There is also a call for courts to better monitor active guardianship cases, as there are no figures that can accurately verify all open cases (Boxx & Hammond, 2012). As of 2008, it was estimated that the number of guardianship cases in the United States ranges from 1 million to over 3 million cases (Uekert & Van Duizend, 2011). In 2010, The Center for Elders and the Courts suggested for state courts to install a system to track guardianship data on case details after conducting a national survey on local court practices and their data collection processes (Uekert, 2010). Without court monitoring, guardians are left without appropriate guidance and supervision, even though there are requirements for guardian reporting that must occur every year (Boxx & Hammond, 2012). The court may also misunderstand the guardians and individuals they are serving at a local level. Although the fear of neglect and exploitation to wards is a current concern in this nation and is addressed with court monitoring, there is also a concern that local courts are not tracking important demographics.

Guardianship programs in Ohio. A state guardianship’s purpose is to serve individuals who are deemed “incompetent”, which in the Ohio Revised Code is defined as “any person who is so mentally impaired as a result of a mental or physical illness or disability, or mental retardation, or as a result of chronic substance abuse, that the person is incapable of taking proper care of the person's self or property or fails to provide for the person's family or other persons for whom the person is charged by law to provide, or any person confined to a correctional
institution within this state” (21 Ohio Rev. Code, 2015). Guardians are court approved during a hearing to take on a “ward” or person/individual under guardianship (the incompetent individual) after a court investigation and clinician evaluation is conducted. Guardians report to the probate court available in each county, who is the overall guardian of all cases (Sup. R. 66.01-66.07).

Individuals who may need a guardian include those with developmental disabilities, mental illness, traumatic brain injury, or severe physical disabilities that affect cognition. Appointment of a guardian is one of the more restrictive means under Ohio law, but ensures the care and safety of an individual that cannot make decisions for one’s self (Ohio Attorney General, 2015). The Ohio Revised Code (Title 21) and Rules of Superintendence (Sup. R. 66.01-66.07) provides a list of effective guardianship rules to be followed in each county court. The Rules of Superintendence regarding guardianship were revised in 2015, reflecting a more person-centered approach for guardians and probate courts to interact with individual under guardianship. (It should be noted that each Ohio probate court may establish more in-depth local rule pertaining to their guardianship practices.) Ohio guardian responsibilities outlined in all forms of rulings include the following main themes: obey orders rules and laws of the court; report abuse, neglect, or exploitation of the ward; seek termination of the guardianship when independent functioning has improved; complete guardianship reporting in a timely manner; show professionalism toward the ward; exercise due diligence in making decisions that are in the best interest of the ward; seek the least restrictive environment for the ward; incorporate person-centered planning when making decisions; communicate regularly with the ward (and possible care staff); be informed about the ward’s end-of-life preferences; and be the ward’s support system (Title 21 & Sup. R. 66.01-66.07). In addition to a guardian’s duties, the guardian may be faced with many challenges associated with the individual’s health and living arrangements. The guardian must determine what is best for the individual to achieve a high quality of life.

Due to Ohio’s passing of new guardianship law, the county probate court that participated in this study is making an effort to increase communication with both wards and guardians in the county through court visits with the guardian/individual and guardian training opportunities (Callahan, 2015). One of the objectives for these visits is to provide court connection with guardians, especially those who are older. The probate court investigator asks a variety of questions pertaining to the health and safety of individuals under guardianship, but the court is also making sure there are smooth transitions for individuals, when a guardian can no longer be in this role. The judge for the county probate court wanted to ensure smoother transitions for the ward, if something would change the guardian status (Callahan, 2015). The purpose of the current study was to target older individuals who may or may not have made or considered plans for their ward and determine how older guardians are preparing for future transitions in the guardianship.

Trends with Older Adult Guardians

Older adult guardian planning practices. With a growing older adult population (age 60 and over) in the United States, planning within guardianships is crucial (Heller & Kramer, 2009). In addition, many guardians tend to be parents of the individual under guardianship, so the courts see an interesting dynamic when both the guardian and individual are aging (McGinley, 2016). Dr. David Braddock presented at a forum for the United States Senate
Special Committee on Aging in 1998 to highlight the issues of the aging of those with developmental disabilities (again, who tend to be placed under guardianship). Braddock coined the term “powerful synergy” to describe the situation of aging parents being responsible for their adult children with disabilities (McGinley, 2016). Not only do aging parents need to deal with their own aging issues, but also of the aging issues associated with their children. When future planning does not occur and an emergency occurs (leaving the guardian absent from responsibilities), “their adult children languish until identified and temporarily placed (McGinley, 2016, p. 153),” in housing or with another person making important decisions.

Trends for the future of certain U.S. populations indicate that guardianship planning is effective. Individuals under guardianship are aging just like the rest of the U.S. population. Adults with developmental disabilities are an example of a population served by guardianship services. It has been projected that by 2030, there are to be 1.2 million adults with developmental disabilities, which shows an increase from the current population of 650,000 (McGinley, 2016). Adults with developmental disabilities are managing their healthcare needs associated with their condition and are living much longer. As previously mentioned, parents (who tend to serve as the child’s guardian into late life) are also aging along with their child. Parents need to make sufficient plans for their child, especially if the parent (who also serves as guardian) passes away unexpectedly. This could result in a crisis for the child, especially if living arrangements and finances are not in place. In addition, “insufficient planning to ensure the availability of services and supports may thus result in considerable hardship for people with I/DD [intellectual or developmental disabilities] when families become unable to offer the level of support they previously provided (NCIOM Task Force, 2009, p. 82).”

Future planning is a key component to ensure a safe environment and high quality of life for the individual under guardianship. Each guardianship case differs and it is important for guardians to carefully evaluate planning options for their individual in order to be prepared for any changes within the guardianship (Ohio Attorney General, 2015). Living arrangements for the individual can be planned by the guardian, such as considering group home arrangements or choosing a long-term care facility. In addition, the individual may need future personal or skilled care for their condition or for aging in general. Another situation that a guardian can plan ahead of time is living wills and funeral arrangements (Ohio Attorney General, 2015). Living wills for the individual under guardianship will finalize end-of-life medical care preferences, even if the guardian is absent. The guardian would need the help of an attorney to have these documents in place. For financial planning, the guardian may also use an attorney to set up a special needs trust for secured monies. Each of these pieces are important to plan ahead, so that the individual can live out their life in the best way possible (Ohio Attorney General, 2015). Local probate courts stress the need for guardians to make these decisions early. Potential outcomes due to lack of future planning on the individual’s behalf include inappropriate living placements or poor medical decisions (Heller & Caldwell, 2009). Therefore, research suggests the need for court officials and legal service providers to reach out to older guardians. This will ensure that there is planning in place for a future transition of guardianship responsibilities and that an individual’s living arrangements, finances, and end-of-life plans are finalized (Heller & Kramer, 2009).
Relevant guardian and developmental disability literature. Past literature concerned with older adults serving as guardians is scarce. Any prior research at a national level has been with a quantitative focus on outcomes of court procedures and tracking of wards (Lisi, Burns, & Lussenden, 1994; Karp & Wood, 2007). From these reports, recommendations were made on better guardianship monitoring practices. There is a significant gap in research concerning the feedback from layperson guardians. Currently, two qualitative research studies have been conducted. Kjervic et. al (1994) conducted a study concerning “incompetent” older persons by analyzing focus group discussions composed of legal professionals, health and social service professional, and family guardians. The themes of the study included self-care, safety, interpersonal relationships, social isolation, and cognition, but the study did not explore themes of future planning for individuals under guardianship. Teaster (2002) conducted another qualitative study concerning guardianship, examining the relationships between wards and public guardians, considering overall ward satisfaction. The study found themes of the importance of preserving the ward’s independence and autonomy and the reporting of wards being considered as “members of the State’s family.” This study brought forth responses from both public guardians and their wards, but it only focused on public guardians’ roles and responsibilities and how this affected ward’s satisfaction with their relationship. What seems to be lacking in the mentioned guardianship related studies is a focus on the transitions of guardians, if the ward “outlives” the guardian.

Looking to literature of older adult caregivers of children with developmental disabilities and mental illness is important because of the previously mentioned idea that parents of these children tend to become guardians. This literature contributed to the understanding of this current study. Certain studies support older adult parents of these individuals and explain trends that are relevant to future guardianship planning including: parents of the developmental disability population do not engage in long-term planning, end-of-life planning is not arranged, future living arrangements are not established, worries surface about future caregiving quality, and parents’ fear of dying before their developmentally disabled child (Griffiths & Unger, 1994; Kropf & Kelly, 1995; Freedman et. al, 1997; Heller & Caldwell, 2006).

One trend seen in literature is that when an aging parent had an adult child with a developmental disability, another child in the family will take on future care responsibilities (Griffiths and Unger, 1994). The idea of the sibling taking on guardianship responsibilities can be also be related to this trend. A study by Griffiths and Unger (1994) had parents and siblings of individuals living with a developmental disability complete a questionnaire concerning attitudes about future planning. Parents (34 mothers and 7 fathers with a mean age of 59.7) and their children (28 sisters and 13 brothers with a mean age of 31.3) participated in the study. Questions targeted the following topics: demographics, family functioning, stress, future caregiving responsibility/future planning, and satisfaction with future plans (Griffiths and Unger, p. 223, 1994). Quantitative analysis was used to compare parent and sibling views surrounding these topics concerning their family member with a developmental disability. Parents reported an uneasiness of siblings taking on care responsibilities in the future due the demand of caregiving tasks and future care quality (Griffiths and Unger, 1994). Although there is worry associated with the future, parents discussed the future of the individual with siblings of the family member with the disability.
Another important trend in the literature shows that older adult caregivers to adult children with developmental disabilities or mental illness need additional assistance in order to continue with their guardianship responsibilities. For example, Kropf and Kelly (1995) pulled from the literature to create case studies concerning older adults serving as caregivers to their adult children with developmental disabilities or mental illness. Two case studies represented common caregiving situations, the “perpetual parents” (parents of children with developmental disabilities) and the “stigmatized parents” (parents of children with mental illness). The authors suggest that clinicians use understandable language when describing difficult medical information to older adults, that clinicians establish rapport with older adult caregivers to create a sense of trust, establish respite services for older adult caregivers, increase outreach to older adult caregivers that may need more services for their child to stay within the home, and provide information to older adult caregivers concerning the future of their child (such as guardianship and estate planning).

Perspectives of older adult caregivers who are parents of individuals with developmental disabilities may lend to an understanding of older adult guardians and their planning process for the future. Freedman, Krauss, and Seltzer’s (1997) research included an analysis of an ongoing longitudinal study that started in 1988 centering on 461 families. Each family in the study consisted of a mother age 55 or over and a son/daughter with mental retardation living within the home. At the time of this study, the sample of families had been contacted at 6 different time periods over the years. At each point of data collection, mothers participated in at-home interviews and completed a standardized assessment. This study’s set of questions focused on residential planning for their son or daughter in the future, including measurement on current caregiver burden and worry about the future. More than a third of the families participating in the study had no living arrangements planned for the future (Freedman et. al, 1997).

The research literature also suggests that older adult caregivers benefit from peer interventions targeted toward developmental disabilities. Improving services and supports, such as through peer interventions, may relate to older adult guardians as well. A study by Heller and Caldwell (2006) tested a peer support intervention (consisting of a legal/financial training session, followed up with 5 small-group workshops) used to support aging caregivers of adults with developmental disabilities for future planning. Twenty-nine families completed a pretest, participated in the intervention, and responded to the follow-up survey. (Nineteen families were in the control group, completing a pretest and follow-up survey.) The average age of primary caregivers was 63 years and consisted of mothers, fathers, and sisters. Follow-up surveys to evaluate the peer support intervention covered the following topics: “future planning activities,” “caregiver burden,” “caregiving satisfaction,” “caregiving self-efficacy,” “discussion with the individuals who have developmental disabilities,” “choice-making of individuals with developmental disabilities,” and “barriers to future planning.” The survey found that 37.5% of families had not arranged end-of-life plans due to a lack of trust with the legal system and professions. Another 35.4% of families reported not being able to afford attorney costs for future planning. Finally, 31.3% of families reported finding it difficult to think about one’s mortality and their child’s future (Heller and Caldwell, 2006).

There are positive trends about who might take on caregiving within a family, which can also be applied to guardian circumstances. For example, Heller and Kramer (2009) found that
often siblings expect and want to be involved with a sibling who has a developmental disability. Their study targeted how siblings planned to be involved in the future of their siblings with developmental disabilities. The survey measured future planning activities and plans, measure of the current relationship, caregiving appraisal, and demographics from a sample of 139 adult siblings (age 18 to 62) recruited from an online sibling list and a sibling conference. Surveyed siblings wanted more involvement in the future planning process. Although parents have discussed or asked siblings to take on care responsibilities in the future, this was where the participation paused for the time being (Heller and Kramer, 2009).

Overall, there is relevant literature about future planning about individuals with developmental disabilities or mental illness. However, none truly capture the guardianship experience or the feelings of guardians. At this point, it can only be assumed that guardians face similar trends as older adult caregivers or parents of those with developmental disabilities or mental illness. More is needed to understand how older adults are planning for a transition within a guardianship. There may possibly be more consequences when there is a lack of future planning when older adult parents are also guardians.

Method

Research Strategy

Qualitative methods were used to collect data concerning guardian perceptions on their role and future planning for their individual. By using a descriptive qualitative approach, the researcher explored various aspects of the guardians’ thought process concerning the future of their wards. This specific approach focused on the guardian experience, as qualitative methods are commonly used when little background literature of a topic exists and when the researcher’s emphasis is not on theme development from interview data (Elliot & Timulak, 2005). There was an overall interest in seeking to understand how older guardians are planning for the transition of guardianship once they can longer assume the role and continue with responsibilities.

Sampling

In this study, the population consisted of guardians supervised by a county probate court in Ohio. Inclusion criteria were: age 60 or over, having served as a guardian for at least one year, and the population of interest included guardians age 60 and older who have had the responsibility of handling the living arrangements and medical decisions of an individual under guardianship. Targeting this age range ensured a longer length of guardianship (there are a significant number of cases that were opened in the 1970s) and this is also a common time for the probate court to see transitions or changes within guardian roles. Study participation was open to all county guardians fitting the criteria. Participants’ characteristics ranged in gender, ethnicity, and socioeconomic status. The guardians may or may not live with their ward. The ward’s reason for guardianship differed among guardians including those with developmental disabilities, mental health issues, alcohol and drug dependencies, traumatic brain injuries, etc.
Recruitment

Participants were recruited at guardianship trainings held by the county probate court. Potential volunteers signed up during a short research presentation and explanation of the interview process. Twenty-six guardians were interested in being interviewed and provided their phone number and home address for contact.

Interested guardians were contacted by phone approximately one month later. Starting at the top of the list, each person who signed up was contacted for a potential interview. A screening process for eligibility was conducted by asking the following two questions: 1) “What is your age?” and 2) “How many years have you been a guardian?” If the guardian’s age was 60 or older and was not a newly appointed guardian (1 year or less), then the individual was scheduled for an interview time.

The interview process was explained to each participant, both at the time of scheduling and before the start of the interview. It was important to be clear that information shared in these interviews would not be reported to county probate staff and that identities would remain anonymous in the final report. This was to ensure that participants felt free to describe their specific guardianship situation and, also, that the interview would not lead to any changes in guardianship status. Confidentiality agreements were also sent to participants, allowing for participation in the study and for the use of recorded interviews.

The phone calling process for recruitment and interviewing process occurred simultaneously, as voicemails were left for participants that did not answer the phone at the time of screening. Once ten participants were recruited and completed phone interviews, it was decided that this was the targeted number for this study. It also seemed that ten participants captured the rich description needed to answer the study’s research question.

Data Collection

The primary method of data collection was through semi-structured interviews, with the use of topic guides (See Appendix for “Topic Guide”). Questions were divided into two sections including “Guardianship Background” and “Future Planning,” which was explained throughout the interviewing process to participants. Interviews ranged in length from 30 minutes to 1 hour and 20 minutes. After obtaining consent from the participant, interviews were audio recorded.

Participants were enrolled and interviewed until saturation occurred. Data saturation occurred when no new information appeared across participant data, no new development of response topics, and enough information was reached in order to replicate this study (Fusch & Ness, 2015).

Data Analysis

After the interviews were conducted, audio-recorded data was transcribed verbatim and audio checked for accuracy. Qualitative analysis through a descriptive approach (Elliot &
Timulak, 2005) was performed on transcripts, with the aid of qualitative coding software (Dedoose, 2015).

**Descriptive analysis process.** Identification of the most meaningful participant responses occurred through the following steps: 1) Reading through the data several times provided greater understanding of the data content, 2) Each transcript was coded to identify certain “meaning units” and responses were sorted into different domains, according to topics of guardianship roles and responsibilities, future planning, and shared feelings or experiences. Dedoose software (2015) was helpful in examining topics and linkages across participants during the coding process. 3) After consideration of codes and sorting into data domains, findings were framed out of the mentioned asked questions: “Can you tell me what your responsibilities are as a guardian?”, “If you could write a book about your experiences over the years and you wanted to give advice to new guardians, what would you suggest?”, “Have you thought about who might take on the guardianship when you can no longer take on the responsibilities of a guardian?”, “Have you done any end-of-life planning for your individual?”, “Have you thought about potential living arrangements for your “individual” once you pass on?”, and “What worries you most about the future?”. 4) The main findings from these questions included these categories: “Future Transitions”, “Parent Roles & Guardianship Responsibilities”, “Worries”, and “Advocacy & Advice”. These four main categories were the most critical among participant reactions during interviews and also captured the essence of the guardian experience.

**Data verification.** Data verification took place in two ways during this study. First, comparison was conducted between notes taken during interviews with transcribed interview data. This ensured that the researcher recorded participant feelings and responses for later analysis and it also eliminated researcher bias during reporting (Maxwell, 2013). Another data verification technique was collecting rich data during the interview process. The hour-long interviews produced enough material and description “to provide a full and revealing picture of what is going on” (Maxwell, p. 126, 2013). Both of these procedures helped in making a foundation for the conclusions of this study.

**Results**

**Participant Characteristics**

Ten participants were interviewed for this study. Guardians had a variety of relationships with the individual under their care including mother, father, sister, and son. The age of participant guardians ranged from 60-65, 65-70, and 75-80. The reasons their individual was under guardianship included developmental disabilities, cognitive impairments, and other mental illness that affected competency levels for decision making. Participant characteristics are included in Table 1. (Only age ranges are used to protect the identity of the participants.)
Table 1: Participant Characteristics

<table>
<thead>
<tr>
<th>ID</th>
<th>Guardian Relationship</th>
<th>Guardian Age</th>
<th>Individual’s Sex</th>
<th>Reason for Guardianship</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mother</td>
<td>60-65</td>
<td>F</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>2</td>
<td>Father</td>
<td>65-70</td>
<td>M</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>3</td>
<td>Sister</td>
<td>60-65</td>
<td>F</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>4</td>
<td>Son</td>
<td>65-70</td>
<td>F</td>
<td>Cognitive Impairment</td>
</tr>
<tr>
<td>5</td>
<td>Mother</td>
<td>60-65</td>
<td>F</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>6</td>
<td>Father</td>
<td>60-65</td>
<td>F</td>
<td>Cognitive Impairment</td>
</tr>
<tr>
<td>7</td>
<td>Mother</td>
<td>65-70</td>
<td>M</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>8</td>
<td>Sister</td>
<td>75-80</td>
<td>M</td>
<td>Mental Illness</td>
</tr>
<tr>
<td>9</td>
<td>Mother</td>
<td>60-65</td>
<td>M</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>10</td>
<td>Mother</td>
<td>60-65</td>
<td>F</td>
<td>Mental Illness</td>
</tr>
</tbody>
</table>

Findings

Four questions from the interview guide prompted the most thought-provoking responses and provided the response categories: “parent role & guardianship responsibilities,” “future transitions,” “advice,” and “transition worries.” Each category is expanded upon with separate sub-categories that were most important to guardians during the interviews.

Parent Role & Guardianship Responsibilities

The response category of “parent role & guardianship responsibilities” came from the interview guide question, “Can you tell me what your responsibilities are as a guardian?”

Showing best interest. One of the main responses associated with guardians and their thoughts on responsibilities was that acting in the “best interest” of their individual was at the center of their perceived duties. As one participant stated,

Again, what's best is for him is not necessarily best for us…To let you know, we believe yes, even though he is in an independent home and everything we are not going to abandon him or anything else, and say ‘hey, he's now the state's responsibility or the court's responsibility.’ We still want to be very active in his life. You know, so in essence the placement was good that we did, and that's what we wanted. We wanted to make sure he was placed before we couldn't do it because, you know, we were getting older and we wanted to make sure that, if you look at it I'm 66 and you figure he's been there since I've been 60. You know, at 60 that'll make you think, wait a minute ‘what's best for him?’ and that's what's best for us (Participant #2).
The previous quote reflects the guardian’s concern with their age and knowing they cannot care for their individual as they continue to age. This guardian believed it was in their individual’s best interest to move into a group home, where safety and care would be offered. The guardian wanted to remain involved in their individual’s life, but knows that he/she cannot be a caregiver later in life.

Another main component of “showing best interest” for the individual is the idea of overall safety in their environment and quality care. This was a main concern to aging guardians who were interviewed. One participant stated, “Oh god, just be there for them and don't leave them, and just not to leave them. Cause if you leave them and let them go then you're in trouble, you know, they're in trouble, and…it don't necessarily have to be in the home but somewhere where she's safe (Participant #10).” This guardian’s primary responsibility was to keep her individual in a safe and healthy environment for a high quality of life. This guardian went on to explain her individual’s situation, and that as a parent, it is her responsibility to look after her. The guardian wanted what was best for her daughter and she will continue to look over her affairs until she can no longer assume the responsibilities of guardianship. She explained that she has been doing this her entire life and want to keep involved in her daughter’s medical decisions and living arrangements.

A continuation. Parents that took on the guardianship role felt it necessary to explain the role of guardian and what guardianship responsibilities meant to them. Duties of guardianship as a parent was explained as, “It doesn't change your parenting style or anything. It's still your child, you still do everything you do, it's just the legality is on the trajectory much more…The rest of it is being a parent. I mean, it just changed the legality of it that's all. Everything else is basically the same (Participant #6).” A continuation of the parenting role was expressed by guardians who had children with a developmental disability, mental illness, or other cognitive impairment. The main point of this statement shows that the guardianship role incorporates the overarching need for legality and the rules that encompass the situation. The parents know that guardianship is needed, but it does not change the role of parenting with their individual. A guardian explains, “Um, I think first what we were just talking about would be, you know, educate yourself, you know, about what's involved and what your real responsibilities are, but as we talked about being a parent is a responsibility and it just evolves into being a guardian. It doesn't seem to change that much except for the official reporting (Participant #7).”

A guardian concluded that the official reporting responsibilities involved with probate court is an additional part of the job, but it does not change the parenting role. Guardianship is viewed as an extra component of being a parent to individuals with developmental disabilities, mental illness, or other issues. The responsibility of being a parent does not change, just because there is an appointment of guardianship. Some do not feel that having the guardianship is that much more difficult. Another participant stated,

And, um, but as far as hard, I don't look at it as hard. I look at it as they're my children and I'm going to do what I need to do until I just can't do it anymore, which I'll do it or bust…Yeah, it's more of a parent thing. It's, I know I had to have the guardianship because that's the rules when they turn 18, um, gosh there are so many things I'd like to change if I could though….So many things so much more important, you know. I mean,
I just do what I need to do…And to me being a guardian, I don't look at myself as a guardian. I look at myself as a mother…And that's just what I do. I, um, guardianship is a paper I have to have…But, and when I go to get them treated because they can't talk and everything I've got to give them that, but like I said I always look at myself as a mother (Participant #9).

This statement shows how there is the underlying need for rules and protection of the individual under guardianship, yet this does not harm or change the relationship between the parent and their child. This mother felt that guardianship enables them to continue with their role, especially with medical treatment. She continued making decisions for her child as a mother, but with the guardianship in place. There was a general feeling that some guardians still saw themselves as “the parent,” rather than “the guardian.”

Future Transitions

The response category of “future transition” came from the interview guide questions of “Have you done any end-of-life planning for your individual?” and “Have you thought about potential living arrangements for your “individual” once you pass on?”

**End-of-life planning.** Most interviewed guardians had some sort of planning in place for the future of their individual. Common plans in place included a burial plot and other funeral related arrangements. What was most interesting is that many of the guardians had not yet developed living-wills. When asked about future care plans, most guardians said that they might have discussed this with the future guardian they selected to take on the role (such as other children of the guardian), but many did not have this in writing. It was a sensitive subject for some, although many were up front about getting older and the need to consider the issue. One participant stated,

Um, yes. I have purchased his burial plot and basically most of his funeral. So that's in process. I have a process in my will that puts money into the state, I forget what it's called now. It's a state trust…That allows for extra things that Medicaid or, you know, Medicare doesn't pay for. Um, I have a will that takes care of what I'm allowed to do with him because of his funding. So I have all of that in files and, you know, I've talked to my other two children about all of that (Participant #7).

Others discussed that these medical decisions surrounding end-of-life would come up at a later time, due to the progression of the illness or condition the individual may be going through. One guardian explained her specific situation,

You know, somebody will say well do you have a living will, do you have this, do you have this? No because, you know, you go asking someone okay are you going to do this, are you going to do this, are you going to do this when something happens? Well, really. Ten years ago I couldn't tell them what I was going to do for him…Because he wasn't this bad 10 years ago…So I make decisions as I feel it's best for them. And you have the right to change your mind even though you signed anything you signed, you have the right at the time to change your mind and call the shots…Which is, you know, which is very
important. It's hard enough to go through and take care of children like this, you know, you know when, and to think of people that have family members that they have to take care. I don't care what age it is or whatever you can never prepare yourself for things that happen (Participant #10).

In this guardian’s situation, she explained she cannot fully plan ahead for these end-of-life circumstances. She will not know how to deal with her son’s quality of life in the future, but knows that she wants him to be comfortable. She would rather not have something set in stone with the variability of her individual’s condition. This feeling of future uncertainty involved with the health of individuals is hard for many of the guardians to plan for. They would rather let the next guardian make the decision in the best interest of the individual, but have discussed their preferred future direction medical decisions, without pressuring oncoming guardians.

Living arrangement planning. When asked about future living arrangements, many had an idea for the future or had a plan in place. The guardians did include aging factors into the situation for their individual, accounting for accessibility issues and the possibility that he or she would need nursing care in the future. A guardian shared,

“Yes, the intention is that [the individual’s current residence] would be where he lives as he ages and, you know, we've started having some conversations, this is a parent group, um, you know, if something happens is there extra help that can come in, you know, hospice could come in, you know, something as they age. Um, can he stay where he is and, you know, what happens with the aging of seriously autistic adults is something that everybody is struggling with...(Participant #7).

This parent specifically chose a living arrangement that will care for individuals throughout the lifespan, bringing in extra care in the future if the individual would need it. The guardian wanted to have this plan in place before her responsibilities were transferred to other children, so that they did not have to make these types of decisions, it was already planned for.

Other guardians stressed the planning for the future living arrangements of their individual. One guardian stated, “We, you know, we try to put together as many contingency plans as possible. Our family has always had this little saying, you can either create your own good luck or you can create your own bad luck. Typically, planning creates your own good luck, and there are people that do no planning and just hope things work out for the best (Participant #4).” This guardian and involved family believed that planning ahead will create the best situation possible for their family member under guardianship. By choosing the facility for their individual, they felt the best care is ensured and that they can live out their live in a safe environment. Most guardians with an individual demanding high levels of care had planned for future living arrangements. This brought peace of mind to many aging guardians about one aspect of the future.

Advice
Common responses concerning “advice” came from the interview guide question, “If you could write a book about your experiences over the years and you wanted to give advice to new guardians, what would you suggest?”

**Advice to new guardians: Advocate!** When discussing advice for other guardians, many stories were shared in which guardians’ advocated for their individual. Stories and examples were mentioned at times when the individual was eligible for guardianship and when they were not yet considered a “ward” by the court. Interestingly, guardians would chose to share stories from throughout their individual’s life to make the point about the significance of advocacy. One guardian shared,

> My first suggestion to any guardian, and I have given this very publicly out there and I've told other guardians already this, is don't be silent. In other words, you think you see something wrong and I don't care if it's from the county or whatever, speak up, okay. Um, and I will give you an example okay? 'We lived in [state] for a while and R went through the educational process down there, okay….The process of transitioning into the day program got to be a problem (Participant #1).

Here we see how the guardian knew that his individual was not getting the services he needed and went to state legislatures in order to advocate on his behalf. The guardian went on to explain his story,

> I first started on Monday calling State Legislature. The second day I called Federal Legislature, and the third day I called the governor's office… ’ And yeah that's why I said parents of handicap cannot be timid, you've got to go for everything and make, if it's a political matter like this of funding or something, you make the politicians answer regardless. In other words, it's the old adage the ‘the squeaky wheel gets the grease’, and that's what you have to be. To me that is the best advice I can give any guardian (Participant #1).

This guardian explained that in order to make sure your individual is getting the proper services, the guardian must advocate on their behalf. This may be an extreme example of how guardians get what is needed, but across all guardians, there was a sense of the importance of advocating in the best interest of their individual.

**Difficult decisions.** Guardians were willing to share experiences over the years that made making medical decisions and living arrangements difficult. The internal struggle in making a challenging decision for the best outcome for their individual was a common feeling amongst guardians. These specific stories were significantly difficult situations to contend with when it came to the best interest of the individual. These stories captured the advocacy involved with guardianship responsibilities, as some difficult medical and living arrangement decisions need to be made for the ward’s quality of life. They were stories meant as advice for other guardians. For example, one guardian shared the most difficult health care decision she made for her daughter, which she still thinks about now that they are both older.
I think the hardest decision I ever had to make with her was um, [individual] when she got her monthly period, they were very heavy. I mean it was like turning on a water faucet, um she couldn't hide it. I mean, she had to stay home from school, I would have to miss work, and finally took her to a doctor and they tried several different things and nothing seemed to work. So they had to put her to sleep and do an exam and do an ultrasound, and the option to keep her from bleeding every month was to do a hysterectomy and she was only 14 years old. I mean, she suffered dearly. That was one of the hardest decisions I ever had to make for her…You didn't want her to suffer and to go through that every month, I mean she would never be able to grow to get married to have children, and a mother's greatest fear with a female childlike [individual] is that somebody would get a hold of her and abuse her, and you know they even said, you know, well then she wouldn't be able to get pregnant. I said that's, you know, a big concern but the bigger concern was putting her through a major surgery and her only 14 years old but, you know, between the doctors and us we made the decision to go ahead and do it (Participant #1).

This showed how the guardian was still dealing with the repercussions of this decision. It was important enough to bring up in our phone conversation.

**Communication.** Guardians stressed that talking with other guardians or related professionals are essential to introduce a newly court-appointed person to these responsibilities. Communication strategies were regarded as an efficient way to transition into the new role and learn responsibilities first-hand from other veteran guardians. It is not only beneficial to discuss court reporting and legalities, but it can also be a way to gain advice on decision-making for living arrangements and medical decisions. One guardian explained,

The first thing I would tell them [new guardians] to do is talk to people that have been guardians for family members. Um, that have been guardians for some time and understand the total scope. I think if you are, for example, if you're an attorney and you're a guardian for somebody and you really don't know them, that's all together different. When it's your mother or your child or something, that's different, and I think you need to speak to those people (Participant #4).

This demonstrated the importance of talking to people who are in a similar situation as the new guardian. It may be easier to transmit information through informal contact and potentially eliminate the, sometimes confusing, legal jargon used by guardian professionals and probate attorneys. This quote further explains the benefits with talking to other lay-professional guardians: “Get involved with others, learn from others, not just the courts. The courts are overwhelmed, too busy. Um, but to get with other people within the community that have the same children or wards, they don't have to be their children of course, but um, to learn what they're doing (Participant #6).”

Using other parents or other guardians for information is a great way to tap into learning resources that go beyond the traditional court format. The overall feeling toward the court is positive and guardians encourage the need to work well with staff and court officials. In addition, the benefit of a multifaceted support system is another key to guardianship success.
Another guardian explained, “You have to have a good support system, nobody can do it on their own. You have to have the care providers, you have to have different doctors, psychologists, caseworkers, case managers, uh you have to have family and friends, a very good support system (Participant # 1).” Integrating all the people tied to the individual under guardianship for knowledge will help new guardians adapt to the role. Older adult guardians encouraged the use of a support system in order to meet the needs of the individual.

**Transition Worries**

The common replies regarding “transition worries” came from the interview guide questions of “Have you thought about who might take on the guardianship when you can no longer take on the responsibilities of a guardian?” and “What worries you most about the future?”.

**Family transition.** One of the many worries for a guardian was who will take over the guardianship responsibilities when they can no longer take on the role. When speaking with aging guardians, either they had someone in mind or they have spoken to the individual about taking on the role. Most guardians had a family member that they would like to be a future appointed guardian. One guardian explained her situation and what her hopes are for the future,

Well, my husband and I back up each other and, um, I don't know. I would hope one of my boys would, but that's not something I've really, really discussed yet. I do know that I need to because I can tell you right now if he was put in a rest home he wouldn't last a couple months. Been there, been in all of them…No, no. Someone like [the individual] has to be in a place that they're loved and gave attention, and yeah. So I'm hoping one of my boys will, but I guess the reason I don't think about that too much about is because of the condition and…Unless something was to happen to me in an accident, I know my husband would take care of them, so...(Participant #9).

In this case, either parent (current guardians) would take on the role, with the guardian’s sons taking up the guardianship in the future. This was something that the guardian has already thought about in terms of a possible transition of duties. Other guardians discussed how they have already chosen the next family member for the guardianship. These conversations might have already included what their wishes are regarding the individual’s quality of life and future living arrangements. These future decisions will be challenging for oncoming guardians, but they must do what is in the best interest of the individual. One guardian explained what he talked about with his daughter when he asked her to take on the guardianship for a sibling in the future. He said,

I've told her periodically what she is going to have to do and I said, ‘this is going to be some tough decisions she is going to have to make.’…I said, ‘most likely [the individual] will end up in a nursing home…that's going to be tough, but you have to look at his life. [The provider] will most likely come to you and say hey things are getting more difficult’, and you work with the support coordinator and you evaluate the situation. (Participant #2).
He emphasized the fact that there will be many factors at play when making decisions in the future and that she will need to do what is best. It is a worry for the current guardian about this transition, but a discussion has helped to put some planning in place for the individual.

**Caregiving quality.** The unease associated with future care of a guardian’s individual was obvious among participants during these phone conversations. Making medical and living arrangement decisions in the past have truly influenced the anxiety among the answers to topic of “worries.” One participant stated,

Really, the one thing that worries me about [the individual] is, you know, she is in a group home with two other ladies, and one of the ladies has parents and family and a good support system like [the individual] does, the other girl does not. She just has nobody and, you know, nobody comes to visit her, nobody takes her out on outings or gets her for holidays or anything, and I have been very concerned that, you know, I just wonder if my son will do as much for her as I do or is [the individual] going to end up like [his roommates] you know, there with nobody. He swears that that will not happen, but you know, it's something I think about. I worry about it, and you know, he swears he will take care of her, but I know that he won't take care of her like I do, you know (Participant # 1).

This guardian has a true concern for the care of her daughter. She does not want her to be lonely, like her roommates and hopes that her son (the potential future guardian) will not let this happen. She states that as her mother, she fears that her son will not oversee quality care as she does. Another participant also showed concern about future care,

Basically what it amounts to is [the individual’s] care in the future at the residential place that they do not get, in other words, sloppy and downgraded. I know once in a while right now I periodically get upset with some…so I will let [the provider] know, and they want to know if I'm over at the house, if something happened…and I know they have sometimes problems recruiting people and I've told them it's easy to get people, qualified people, all you have do is pay more, okay? ..yes that is kind of a big political battle, educating the politicians and educating the public (Participant # 2).

From this direct quote, the quality of future care resonates with other guardians. This guardian recognized the issues with direct care workers and their pay rates. He feared that pay rates caused poor caregiving services, so if this does not change in the future, he worried about the caregiving quality for his individual. Another guardian expressed this concerning future care quality,

Um, will there be enough watching of things for him in the future in the way that I've tried to do that. I know it will be different, I know it won't be the same, um, because I'm his mom (laughter). You know, so I know that that's going to change and I think that is the hardest thing for me, particularly because his medical needs are fairly intensive and I don't know where his seizures will go in the future and, um, you know, he's on medications that could cause diabetes and, you know, so there's just a lot of things, and I
would suspect that I worry most about his medical care because I'm so involved in that now because it's been so challenging (Participant #7).

This guardian, who is also the individual’s mother, has the worry that care will not be equivalent to the care she gave over the years. She is worried that his medical needs will not be paid close attention by staff. She knows that the future care is something that she cannot control, so it was one of her main concerns.

“Outlive me”. A common concern among older guardians (especially who are also parents), is that their individual will “outlive” them and they do not know what the future will bring. When the question was asked “What worries you most about the future,” many guardians expressed right away their fear was that they would pass away before their individual. A guardian’s initial response to this question was, “Um, well, me passing on before him…and as healthy as he's been, I mean, that's, that's probably likely. He might live until he's 90 or 100; I don't know (laughter) (Participant #8).” Another guardian’s immediate response to this question was,

You know, I worry about somebody, something happening to me and who is going to take care of her properly. That's my biggest concern, you know, who is going to watch over [the individual]. I don't know yet. I know her brother has automatically said he's going to,…So, you know, that's a possibility…you have to be, you know, more laid back and just kind of let it roll. (Participant # 5).

These responses show the uncertainty of what may happen with the guardianship and the future of their individual. Other statements from parent guardians dealt with general uncertainty in future services related to the individual,

I mean, you know, wondering what the future is going to bring is, you know, when you're not there to do something and you don't know what the government is going to do with money, you don't know what is going to happen with, you know, systems and healthcare and all of that. I think probably where's the money going to come from in the future is also a big worry because, um, the rise in autism and the cost that's involved in that is going to bankrupt the government and, you know, I'm very very concerned. Um, I'm a [health-related job], I see a lot of people with autism, a lot of young kids, and it's just overwhelming. So I really worry about, you know, things that I don't have any control over (laughter) sometimes and then you try not to worry but, you know, that is a concern (Participant # 7).

There was also that feeling of confusion as to who will be looking out for their best interests when their parent is gone. Another guardian explained the situation,

And when you first talk to her you wouldn't know that she's got the issues but then, you know, later on in the conversation you'll understand that she's got some issues, but a lot of people don't understand that. They think that [the individual] is okay, but she's not, just by looking at her, you know?..But it's so hard, you know, to find something for her…If [the individual] could be somewhere where she has supervision, that's her only
thing. She needs to be watched. She needs supervision. She can do it but, you know, it's hard to find supervision for her, you know? (Participant #10).

Overall, there was a sense of worry when it came to who would be watching over the individual in the future. Guardians want what is best for their individual, but know that they cannot control the future. They can only plan as much as possible and hope that future guardians and services will be geared in the best interest of their individual.

Discussion

The purpose of this study was answer to the following research question: What are older guardians’ plans for their individual under guardianship when he or she can no longer continue the responsibilities set forth by a county probate court and Ohio Law? In-depth guardian interviews brought forth perceived experiences and feelings concerning the guardianship process, that may be unknown to probate court staff and others involved in related guardianship services. An analysis of the transcribed interview data exposed important findings, when framed around certain questions from the interview guide.

Acknowledge the parental role

One finding in this study was that guardians, who were also parents, emphasized their roles as a “parent” rather than a “guardian.” This showed that although parents of children with developmental disabilities or mental illness are growing older, they were still being a “parent.” Parents stressed the fact that the guardianship allowed them to stay in the parenting role while having the authority of doing what is best for their child. The main purpose of the guardianship was ensuring safety for the future. The parental role did not discontinue when their child turns 18, it continued well until the parent can no longer assume the role of guardian and beyond. Past guardianship literature does not truly develop the feelings described by parent guardians in regard to their legal role versus familial role. It is beneficial to for legal entities to be aware of this when working with parents who also serve as guardians. By acknowledging the parental role involved in guardianship, it may help in targeting and carrying out future planning efforts for individuals.

Future planning trends

Another observation from participant responses was that older guardians were beginning to think of the future transition, yet may not have planned all elements of the transition. The extent of planning was varied among participants. Observations suggest that the future of the guardianship, end-of-life planning, and living arrangements were important planning trends among older adult guardians. Often parents of those with a developmental disability or mental illness do not engage in long-term planning for their child (Freedman et. al, 1997; Kropf & Kelly, 1995), but this study revealed some differences in planning preferences compared to past literature. Findings suggest that most guardians had a discussion with other family members or friends about possibly taking on guardianship responsibilities in the future. If the individual under guardianship had a sibling, that sibling appeared to know the responsibility might fall on them. This supports the literature of involving adult siblings becoming future primary caregivers.
(being a legal guardian, trustee, or a general caregiver) when parents must transition care-related responsibilities (Heller & Kramer, 2009). Some parents have had that conversation and other guardians reported putting it in a will. Again, this is supported by literature (Griffiths & Unger, 1994), saying that a majority of parents (who may or may not be guardians) have discussed future living arrangements with other siblings of the child with a developmental disability. Participating guardians of this study had a few people in mind for the future and reported that when the time comes, the guardian will call upon these people for appointment.

Another finding was that guardians for the most part reported having funeral arrangements and burial plots in place for their individual. When asked about the medical decisions surrounding end-of-life many guardians did not have plans in place, such as a living will. Past literature indicates that aging parents of individuals are more likely to make legal and financial plans (Heller & Caldwell, 2006), suggesting that future medical decisions may not be as thought out ahead of time. The perceived obstacles of planning end-of-life arrangements might be possible reasons including: finances associated with an attorney, being overwhelmed by the process, having a lack of correct or available information, and possible emotional issues to thinking about one’s own mortality and that of the individual (Heller & Caldwell, 2006). Guardians stated that instead of having a prior plan in place, they would like to make that decision when the time comes (if that guardian happens to be present or not). Expression about end-of-life from the participants in this study truly depended on the severity of the individual’s health and that quality of life should be evaluated at that time, rather than years in advance. Perhaps this feeling is connected to the daunting process of getting documents and planning in place (Heller & Caldwell, 2006), but no literature was found directly linked to the severity of health with and individual and how end-of-life care is planned.

Another future planning finding was that living arrangements tended to be thought out or put into place early. This was inconsistent with Heller & Caldwell (2006) stating, “some researchers have reported that fewer than half of families have made plans for future living arrangements” (p. 189). Most of the guardians in this study had an idea or plan in place for the future residence of their individual. Because the guardians were older, they wanted to make living arrangements well in advance, especially if future health care would be an issue for the ward. Freedman (1997) discussed that aging parents with a child with a developmental disability face the “residential placement stages” including, “no discussion of future residence,” “early discussion but not serious in nature,” “alternatives considered without resolution of choice,” “provisional or tenuous plans made,” and “definite residential plans established” (p. 115). These stages ensure the placement of an individual and require a lot of thought for those responsible for individuals with a developmental disability. Many guardians said that having their individual living independently enabled them to already experience that transition of being on their own and gave guardians greater piece of mind for the future. Other guardian responses met other “residential planning stages” (Freedman, 1997).

Guardian advice

Another finding involved three main areas of advice for new guardians including: advocating on behalf of your individual, knowing that difficult decisions will be made at some point during the guardianship, and that communication with other guardians and professionals is
critical to a successful guardianship. The first piece of advice dealt with being an advocate for the individual under guardianship. Frequently, guardians spoke of times when they had to go to administrative officials to get certain services in place for their individual or to improve the quality of their care. Guardian wanted what was best for their individual for an increased quality of life, which is not reflected in past qualitative guardianship literature. It could be beneficial to do more research on this topic for future guardianship planning purposes. The second piece of advice was for new guardians to meet with other guardians in the county or guardianship-related professionals to ‘learn the ropes’ of this new role. Communicating with others about challenges associated with the guardianship can help one learn new strategies when interacting with court officials or carrying-out responsibilities, in addition to, learning what needs to be in place for the future. Guardians stated that it is overwhelming at first when learning legal terms and the court process associated with guardianship. Reaching out to others in a similar situation can be beneficial to filling gaps in knowledge. Support from Heller & Caldwell (2006) lends to this topic, stating that peer support modeling is a useful means of learning between caregivers of those with developmental disabilities, especially for information concerning future planning and caregiving services. The final piece of advice was to essentially ‘listen to your gut’ when faced with making difficult health care decisions for their individual. Over the years, guardians may be faced with health situations that can be confusing to the guardian when they must make a decision. Guardians gave past examples that showed their thinking process and that these situations helped them in planning for the future of their individual. This feeling described by guardians has not been adequately described by guardianship literature over the years. Future research on this topic could help health care providers working with the individuals and probate courts understand the decision making process of layperson guardians.

**Worries about the future**

The last finding from transcription analysis showed that older adult guardians had three major worries, including the how the family would transition in the future when they are no longer guardian, what the quality of caregiving would be like, and if there would be enough services to support their individual in the future. Guardians often reported their “worries” as questioning who would be taking on the guardianship in the future. Again, most guardians either had a discussion with this person or have someone in mind, as seen in past literature (Heller & Kramer, 2009). The worry here was associated with overall transition of the family (if the oncoming guardian is related to the individual) when the guardianship is passed over. Some participant guardians, whom were also parents of the individual, hoped that other family members would not have to take on this role; that the individual will not outlive their parents. Others discussed with the family member that there would be challenging decisions involved when taking on the guardianship and that they must do what is in the best interest of the individuals, not for themselves. Heller and Kramer (2009) was inconsistent with this finding, stating that “few families made plans or involved siblings in planning” (p.208) for the future, but many siblings expected to take on some sort of role when their parents could no longer assume care responsibilities. Another worry was that the future caregiving quality would not be as superior as when they were guardian of the individual. Older guardians have always felt that they could watch out for their individual and that once the transition occurred, the new guardian would not be as mindful of care or other factors associated with quality of life. Kelly and Kropf (1995) reported that among aging parents with adult children with a developmental disability or
mental illness, the uncertain future concerned with their child’s caregiving quality is one of most frequently reported worries. The final worry dealt with the uncertainty that the future will bring if the individual “outlives” their guardian. There was a general worry among all guardians about the future, hoping that the quality of care, living arrangements, and funding would be enough to support their individual. Heller and Caldwell (2006) reported that U.S. trends show that those with developmental disabilities are living longer and, therefore, tend to live longer than their parents (who usually serve as primary caregivers). This is why planning for the future of these individuals is important and needs to be a priority of the guardian. The older guardians are aware of the imminent transition and know that they cannot control the future for their individual. All they can do is hope that prior planning and oncoming guardians will look out for the individual under guardianship.

**Research Implications**

This research study has several implications for county probate courts in dealing with older adult guardians of individuals with developmental disabilities, mental illness, or other cognitive impairments. This can also be applied in other Ohio courts and their guardianship programs and related service providers.

First, it would be beneficial for the probate court to provide some sort of informal programming targeted toward older adult guardians. Info-sessions related to legal planning for the individuals under guardianship could be highly beneficial to county guardians. Because communication with other guardians and related-professionals was a major part of “advice,” setting up a formal or informal group could be beneficial. While parents and their individual’s situations vary, it could be helpful in providing connections across the county. In addition, guardians would have access to information that may be hard to understand from a formal training or manual. Therefore, a group with set info-sessions and informal meetings could help to reach more guardians and fill gaps in knowledge concerning various aspects of guardianship. If there are barriers for older guardians to attending meetings, provide in-home meetings (possibly attached to the county’s guardianship program visits) to help explain how future transitions may work and how to make sure a co-guardianship is in place, if something would happen.

Another implication realized in this study, is that guardianship staff will have a better understanding of the guardians served in the county and how they perceive future planning for their individual. Aging guardians in this study had various plans in place for the future of their individual. Many had living arrangements thought through or planned for, but did not have concrete plans for a future guardian to take on the role. In addition, there had not been significant planning in terms of end-of-life medical decisions. By addressing some of the worries in an informal setting, guardians can help each other plan for the future. It would be beneficial to have a court representative present for direction of these meetings and “safe-space” for voicing concerns about the future. In addition, better knowledge will be available in how to respond to older adult guardian worries, especially about future care quality and support concerns. This implication can be targeted in county’s guardianship program visits conducted by the probate court investigator and master-level student interns.
The final implication was realized from speaking with guardians in this study and understanding the scope of current guardianship practices. It would be highly beneficial for U.S. courts to keep track of guardianship case demographics to inform local guardianship practices. While some guardianship programs may take case notes during meetings with guardians and their wards and have guardianship paperwork on an electronic filing system, it would be beneficial to track more details on each case. Every local probate court in this nation is different in terms of how they monitor cases and reach out to guardians. (The court used in this study had their own tracking system, but this is not found across all courts.) Probate officials tend to be very knowledgeable about their guardians and individuals, yet a tracking system could be beneficial for more efficient information retrieval. By having more details guardians in a data tracking system, local courts could better target when a transition might be occurring and can help court officials better interact with older adult guardians. Overall, improved and increased outreach to guardians and their individuals could be achieved. U.S. courts can only provide an estimated range on guardianship cases and limited details on the populations served by guardianship services (Uekert & Van Duizend, 2011). A tracking system will not only help to monitor guardianship cases, but could also provide extensive details on the guardians and any future planning that is in place.

Limitations

Not generalizable. Generalizations from this study are limited because it only focused on guardians residing in a particular Ohio county. However, this study does reflect certain findings from other literature, especially concerning caregivers of children with developmental disabilities and mental illness. There is an important connection between these two topics, as parents of these children tend to become guardians in order to make decisions into later life.

Socioeconomic status of guardians. Interviews with guardians inevitably brought out discussion concerning socioeconomic status and education attainment, although the question was not implicitly asked. Observations during interviews found that over half of participants were college educated or higher and that there was mention of high paying jobs. This could possibly mean that these guardians had more access to acquiring services or had more knowledge on how to advocate on behalf of their individual. In addition, this could also result in better resources being available to plan for an individual that other guardians may not be able to take advantage of. (Example: Planning and developing a group home for their individual’s future. OR Setting up a special needs trust for the future.) In addition, hiring an attorney to pay for documents such as wills and trusts can be costly, which not all families with a guardianship can afford. Perhaps, in further research, there could be questions regarding socioeconomic status and education, to get more of a varied pool of guardian participants.

Guardian participants’ thoughts on professional guardians. Another limitation in this study is that all interviewed guardians had plans for a family member to take on the guardianship in the future. There are some guardians that do not have a family member to take on the role of guardian in the future. This means that a professional organization will likely take on the guardianship of the individual. This study did not capture any participant feelings where this is a worry for the future concerning professional organizations. In fact, all guardians that participated in the study did not consider a professional organization as an option for their
individual. In some conversations, the participants did not want to talk further about the subject, when prompted.

**Future Research**

It may be beneficial to conduct a longitudinal qualitative study with these participants. Perhaps contacting the guardian and their individual every five years, eventually speaking with the incoming guardian. It could be beneficial to see how the transition actually occurred compared to the original planning or ideas in place. It would also be interesting to ask the same questions from the interview guide to new guardians and keep following up with the individual to see how the guardianship changes. This may enhance knowledge of the initial transition and help guardianship programs anticipate problems with the new transition within each case.

Another future research topic could be interviewing guardians that do not have family to take on the guardianship in the future. In these cases, the probate court may appoint a professional organization to make medical and living arrangement decisions for the individual. Connecting with current guardians confronting worries about the future of their individual could be beneficial to the court system. Also, knowing if the individual will need a professional guardian in the future will help the court be prepared for the transition. In addition, it may provide peace of mind to the current guardian who is not familiar with the role of a professional guardian. Further research with these specific guardians could help to eliminate or minimize the lag in time when the court is searching for the best guardian possible for an individual, when the original guardian can no longer take on responsibilities.

**Summary**

It is clear that guardians may need more assistance in planning for the future of their ward. The findings indicated that not all parts of planning are established by the time guardians are age 60 and older. It is crucial to have certain aspects of planning in place for the best interest of their individual including: end-of-life plans, financial plans, living arrangements, and a possible future guardian to take on responsibilities. Much of the planning can be overwhelming to guardians, which why it was reported that there was a certain lack of planning in some areas. Participants reported that discussions occurred with potential future guardians, such a siblings or other family members, yet there is a general sense of unease associated with the individual’s future. Worries were linked to the future guardian’s care and planning, as well as, the feeling that parent guardians would not be around to continue that role with their child.

Guardians also reported how advocating for their individual and following their intuition when making difficult medical and living arrangement decisions over the years were some of the best pieces of advice to give to oncoming or new guardians. Communicating from other professionals or guardians in the county would also be a benefit to those taking on guardianship responsibilities. Perhaps these specific responses could help county probate courts in reaching out to older adult guardians that have difficulties in planning. By considering the older adult guardian’s approach to planning, the court can facilitate a better transition. This can be put into place through the suggested informal guardian meetings held by probate throughout the year.
addition, the probate court investigator and graduate students can discuss the topic during county guardian/ward visits, to connect guardians with future planning services. These two methods can help guide guardians through the planning process and make sure that information is reaching them at an understandable level.
APPENDIX A

Glossary of Definitions

**Group home:** A term used in this study to identify a particular living arrangement determined by the guardian for their individual. This is a setting where more than one individual lives within a home environment and receives in-home services (such as assistance with ADLs, cooking, cleaning etc.) with their roommates.

**Guardian of the estate:** A term used by the Ohio Supreme Court (and local probate courts) to distinguish each guardian’s role with their individuals. A ‘guardian of the estate’ makes decisions in the best interest of the individual concerning their personal finances only.

**Guardian of the person:** A term used by the Ohio Supreme Court (and local probate courts) to distinguish each guardian’s role with their individuals. A ‘guardian of the person’ makes decisions in the best interest of the individual concerning living arrangements and medical decisions.

**Incompetent:** A term used by the Ohio Revised Code and various probate courts to describe a person served by guardianship services. A state of incompetence indicates that the individual is not mentally capable of making critical decisions for themselves. This state of capacity is decided by a doctor’s assessment of the individual and the probate court judge during the subsequent hearing.

**Layperson guardian:** A term used in this study to describe court-appointed individuals that are not working on behalf of an agency or legal firm to provide guardianship services or responsibilities. (Layperson guardians are often family members or friends of the individual under guardianship.)

**Living will:** A term used in this study to identify the document used to make future decisions regarding end-of-life care that is used by medical physicians, when an individual cannot communicate their wishes.

**Long-term care facility:** A term used in this study to identify a particular living arrangement of the individual served by the guardianship process.

**Special needs trust:** A term used in this study to identify a particular style of financial planning where the guardian (typically the parent or other family member) sets up a financial account where assets are saved and protected for the individual’s future when it is needed for living arrangements or other needs. Special needs trusts are not taxed and are used by beneficiaries with developmental disabilities or individuals with a mental illness that live into adulthood and old age.

**Ward:** An official term used by the Ohio Supreme Court and probate court officials to describe an individual under guardianship. This term is shifting away to a more person-centered term of
“individual” or “person” when used in one-on-one dialog and training materials, but “ward” is still used during court hearings.
APPENDIX B

Topic Guide

Background Information:

Please tell me what your relationship is with the ward under your care.
Age:

Why the guardianship was initiated? (Health concerns?)

How long have you been a guardian?

Do you share the responsibility with anyone else?

What is their relationship with the ward?

What is it like to share responsibilities?

Does the ward live with you? (No? How long?)

If so, do you help care responsibilities (such as bathing, feeding, grooming, etc.)?

Do you have anyone come into the home and help with responsibilities?

Can you tell me how the group home/residence/nursing facility involves you?

Would you say you are happy/unhappy with overall care here?

Do you provide transportation?

Does ________ attend a day program or workshop? How does he/she like it?

Can you tell me what your responsibilities are as a guardian?

*What is it like to take on these responsibilities?

What have been some of the most difficult situations you have had to deal with as a guardian?

What has it been like to determine living arrangements over the years?

What has it been like to make difficult health care decisions, if any? (Specifics?)

Have you done any end-of-life planning for your Individual?

When you first started being a guardian, how did you learn the process? How has that changed over time?
If you could write a book about your experiences over the years and you wanted to give advice to new guardians, what would you suggest?

Can you tell me a story about a time when you had a difficult time making a decision for your individual?

What is your relationship like with your individual?

**Future Plans:**

Have you thought about who might take on the guardianship when you can no longer take on the responsibilities of a guardian?

If so, why would this person be a good choice? (Background between individuals)

Have you discussed any future planning with “Individual”? Can you tell me what this conversation was like? Were you nervous to share this with them?

Have you thought about potential living arrangements for your “Individual” once you pass on?

Have you thought about health care decisions for your “Individual” once you pass on?

One of the suggestions of the probate court is to bring on a co-guardian to share responsibilities, but also to start the transition process of guardianship and teach the co-guardian their role. Is this something you would consider doing now?

Who might this person be? Why this person?

Do you have reservations about bringing someone on at this point in time? Why?

Have you thought about professional organizations being a potential guardian for your ward?

What worries you most about the future?

Is there anything you would like to share with me, either about how you are feeling about the future of your ward or any other future planning decisions that you might have?
References


