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| **West Virginia State University Department of Social work** |
| **Healthy Grandfamilies Project Focus Group Report: Mosby& Wamsley** |
| **Healthy Grandfamilies Project: A Preliminary Identification of Needs of Chronically Ill Grandfamilies** |
| **Funded by The Office of Research and Public Service** |
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| The College of Social Work at West Virginia State University is committed to developing and delivering sustainable solutions and interventions to families and individuals affected by a variety of social and behavioral issues and problems which reflect changing demographics. The documented growth of grandfamilies providing custodial care for their grandchildren which alone, is a social issue which demands a response from social work practitioners, must be addressed. When caregiving is more complex because of grandparents’ chronic health problems, a targeted response is more warranted. Focus groups offered valuable insight into pressing issues of the emergent family form the subject of this report. |

**Healthy Grandfamilies Focus Group Study Report**

**OVERVIEW**

Unites States Census data reveal that more grandparents, and in some instances great-grandparents, are providing continual care for their grand/great-grandchildren. In these cases, grandparents have assumed the role of parenting (Raicot, 2003) in a family structure outside the scope of their control and often beyond their ability to do so independent of some type of emotional, psychological, financial, or social assistance. What would otherwise be the achievement of an anticipated rite of passage into grandparenthood (Baldock, 2007) has been subverted by the demand to perform a very different role. Prior to the last decade, it was estimated that more than two million U.S. children were in kinship care (Gottlieb, Silverstein, Bruner-Canhato, & Montgomery, 2000). Although there is some disagreement about the specific number of such family arrangements, it is clear from the scientific literature and even from the popular press (USA Today, 2011) that the number is increasing, regardless of the data source. It is further noted that 886, 449 children are reported to be in care in West Virginia; a child is thought to be abused or neglected every two hours in the state, resulting in a reported 19,310 grandparents raising children (<http://en.wikipedia.org/wik/Race> and ethnicity in the United Sates Census) here. Research findings reveal that West Virginia grandparent caregivers are particularly vulnerable to this type of family dynamic because of higher poverty rates (Myadze, 2012). In response to this emerging trend, the term grandfamily has been coined for these surrogate parents (Edwards, 2003) and is gaining popularity among professionals and the public. In this type of care arrangement, grandparents, great-grandparents, other relatives, or even close family friends, are providing custodial care for a child because the biological parents are in situations which prevent them from parenting, or they are unwilling to parent (Strong, Bean & Feinauer, 2010). Even in “optimal” caregiving arrangements, there can be burdens and demands which challenge the caregiver to be as effective as s/he could otherwise be.

When conditions which lead to the grandfamily caregiving are the result of parental impairment, estrangement, mental or physical disability, drug and alcohol abuse or other negative situations, what could otherwise be a joyful response associated with episodic caregiving of a grandchild can instead often be burdensome, emotionally and financially. Children who are separated from their parents as a result of alcohol and drugs frequently face psychosocial, psychological, emotional, and physical problems which can harm cognitive development (Baldock, 2007) If the grandparents have chronic illness, the situation of caregiving can exacerbate their health condition and again place the child at risk of displacement and susceptible to an unfortunate range of negative outcomes. The extant literature reveals that custodial grandparenting is associated with many negative psychological outcomes (e.g., depression, stress, low life satisfaction) and that these outcomes can contribute to negative effects on physical health and mental health. Based on findings from the literature, special needs of the grandchild can further affect caregiver health – physically, emotionally and psychologically (Murphy, 2008; Sands, Goldberg, & Thornton, 2005), especially the grandmother (Musil, Gordon, Warner, Zauszniewski, Jaclene, Standing, & Wykle, 2011).

**PURPOSE & JUSTIFICATION**

The purpose of this focus group study was to identify the day-to-day experiences of grandparents who are raising one or more grandchildren and to describe the ways in which raising grandchildren are perceived to affect the health of grandparents, especially those with chronic health conditions. Because of the concern that such grandparents might need a variety of forms of social support, the study also seeks to identify the types of community services commonly used by grandparents raising their grandchildren and to identify perceived gaps in services and barriers to the use of such services. It was further intended that the focus group study would explore the receptivity of grandparents to participate in a randomized study to evaluate the effectiveness of a chronic disease self-management intervention.

Group dialogue among people who have a shared experience can lead to extensive discussion about these topics in a non-threatening environment. The inherent probative nature of focus group research lends itself to establishing understanding of grandparents who are caregiving for their grandchildren because of the cognitive, psychological, and intense attitudinal character of the situations that are thought to accompany this type of caregiver arrangement. Moreover, focus groups allow the researcher to approach a number of deep structural issues (as well as surface issues) that can determine key topics in the area of interest. Certainly, biographical experiences of the grandparents interviewed could not have come to the forefront in a research approach that is not as fluid as the focus group. The ability to potentially assist grand-families do what do better, without compromising their health, can contribute to children (many of whom have already experienced trauma of one type or another), being raised in an environment where the caregivers(s) do not have to further impair their health because of the responsibility they have accepted.

**METHODOLOGY**

The research team conducted three focus groups in Kanawha County at three locations with grandparents age 50 and older, with at least one chronic health condition who have the primary responsibility of raising one or more grandchildren. All respondents were generally healthy enough to have participated in the study. Representatives of community-based services provided considerable assistance to bring the study to fruition by enlisting participants who met the specified criteria. Data were collected between September 22 and September 27, 2012. Participants were not randomly sampled; rather they were recruited in a purposive sample. Although the original intent was to have two groups of between six to eight participants each for a total of approximately 16 participants, the total of the three focus groups yielded 13 respondents. Initially, there was a concern that with only three participants in each of two groups, inadequate viewpoints would be derived and that multiple perspectives might not be tapped. However, in focus group research, the small size of the group does not necessarily compromise the quality of the data. Instead, the data in the smaller groups was unexpectedly rich, in-depth, and insightful. The mean age for respondents was 64.8 and the median age was 65. The age range was 46-81, indicating that the youngest grandparent was younger than the specified age parameter. This respondent was allowed to remain in the study to gain more insight into life span development issues that could be associated with the lower age. Twelve of the 13 participants were White, one was African-American. There was a span of household resources in terms of finances and human capital. There was an extensive list of chronic problems these grandparents face. Fifty percent have high blood pressure, 40 % have arthritis, 30% have heart disease, 30% have depression or anxiety, 20% have lung disease, 20% have diabetes, 10% have had a stroke, 10% have osteoporosis, and 10% have or have had cancer. Some respondents have more than one chronic condition. The Principal Investigator, a social scientist in the Department of Social and Behavioral Sciences, conducted all of the focus groups and completed the analysis.

Predetermined, open-ended questions were developed in advance by the Principal Investigator and the Co-Principal Investigator, Dr. Brenda Wamsley based on a preliminary review of the literature. The questions were designed to tap into the areas of concern for the study. To ensure continuity of the data gathering and to create a context for the researchers, first, participants were asked what situation or circumstance led to their caregiving arrangement. Next, the respondents were asked to share what their day-to-day routine was like and third, they were questioned about their overall health self-appraisal, and information was requested from them about their need for and access to social services. A copy of the moderator’s question guide which was used for the first session is attached. In the subsequent two focus group sessions, the guide was revised based on feedback received in the first group. The Co-Investigator, a professor in the Department of Social Work, also served as the note-taker and assisted with the analysis and identification of key findings.

**Focus Group #1** met on Saturday, September 22 on the campus of West Virginia State University. It involved three people, two of whom were married to each other and the third participant was a single grandfather. **Focus Group #2** met on Tuesday, September 25 at 10:00 a.m. at Lutheran Church in Charleston. There were 7 participants; two married couples, an 81 year old great grandmother, a case worker who has provided care for grandchildren, and another grandmother who was articulate and appeared to be in her 50’s. **Focus Group # 3** was held on Tuesday, September 27 at Westside Elementary School. The session began at 4:00 p.m. and had three people, two of whom were a married couple in their 70’s who have been married for 25 years. Although the great grandchildren are his “steps” he doesn’t believe in using that word or making that distinction. The other respondent was an African-American female who lost her home in a fire and was living with her sister with her grandson. Ruiz (2008) draws attention to the relative dearth of research on African-American grandmother caregivers considering their prevalence in the grandfamily population. Differences were noted between the context of the African-American respondent and her White counterparts, suggesting that there are likely more differences than we were able to determine in this study. The inclusion of only one African-American grandparent could also be an artifact of their truncated contact with some community-based service sectors as evidenced by the sole African-American respondent in this study not being aware that Habitat for Humanity could be a potential resource to explore permanent housing for her and her grandson.

At the beginning of each focus group, the moderator and co-moderator explained the purpose of the focus group and ground rules for participation, and provided consent forms to document informed consent of each participant in each group. Attention was given to the “creature comforts” of the participants by holding the focus groups in comfortable locations which were easily accessible. Refreshments were provided at each of the sessions. Each participant received a $20 Wal-Mart gift certificate at the end of their session, which was a practical expression of gratitude for their participation.

All focus groups were audio-recorded however, in the interest of speedy analysis, the decision was made to undertake a notes based analysis relying on the elaborate field notes of each 90-minute focus group session. The audio recordings were used to clarify the notes. Although the data cannot be generalized, the findings can be transferred can be used as a basis for considering approaches to intervene in the lives of caregiving grandparents to equip them with strategies to effectively balance their caregiving with their chronic illness. Intentionally, no attempt to quantify the results of the focus group data was made because doing so would not only undermine the purpose of group data, it would not offer a more pronounced understanding of the core issues. Further, any numerical conversion of the data could be misleading. The study gathered extensive perceptions of focus group participants on the complex topic of providing custodial care at a point in their life cycle when they would expect to have a relatively unencumbered life. Following the focus group interviews, each respondent completed two surveys. One was The Help Yourself Chronic Disease Self-Management Program; the other was The Caregiver Burden Inventory. The results of both have been quantified and were the basis for the demographic data and documentation of respondent chronic health problems. The surveys triangulate the data.

**ANALYSIS OF THE DATA**

Data were analyzed systematically to cull out findings that accurately reflect what was shared by participants in the groups. In addition to the analysis being systematic, it is verifiable through triangulation, it is a sequential and evolving process, and it is continuous (i.e., forms of analysis were occurring throughout the data collection rather than waiting until the very end). A key concepts analytic framework was used to analyze the data to discover central ideas and to categorize the results to understand how participants view each topic related to their grand-parenting role. This framework was decided based on the purpose of the study and what it set out to discover.

**KEY FINDINGS**

Clearly, there is an abundance of trials and tests associated with grandparents providing care for their grandchildren within their homes (or the homes of other family members), which have become non-traditional, inter-generational families, skip-generation families ((USA Today, 2011). How to most adequately provide care for the child, and facing a variety of insecurities which are the precursor to a litany of problems for both the caregiver and the child were identified in this study. The risk of problems becoming intractable is a grave concern. Education, housing, avenues of formal and informal social support, and even respite care for the caregivers surfaced as an issue. This is supported by other research to consider the social and emotional needs of members of the grandfamily (Family Strengthening Policy center, 2007; Murphy, 2008; Racicot, 2008). The principal findings from this study are organized around three central conclusions. First, custodial grandparenting has adverse effects on the health of caregiving grandparents. Specific findings in support of this this dimension are:

* The willingness of caregivers to attend a 6-week workshop was positive when framed within the context of their caregiving role. Their specific needs for training focused on stress management, skill-building, communication strategies, approaches to better understand and manage mental health issues of the grandchildren, coping with family dynamics, and disease self-management.
* Effects of grandparenting on health include loss of sleep, high blood pressure, fatigue, and stress related symptoms (anxiety, depression, anger).
* Although all grandparents reported having one or more chronic conditions (high blood pressure, arthritis, heart disease, depression/anxiety, lung disease, diabetes, etc.), they tended to downplay their own health concerns and rated their overall health as being good.

Second, findings from this study confirm the need for support for grandparents to allow them to care for the children more effectively within a context of reduced stress. Accordingly:

* These families are dealing with multi-faceted situations which place them under tremendous stress (dealing with adult children, grandchildren with mental health and behavioral issues, financial strain, lack of support from school systems, and a sense of loss of traditional roles associated with grandparenting and later life). There is some indication that there is role strain.
* Support comes primarily from spouses, family, friends, and religious faith.
* Grandfamilies universally reported problems with the child welfare system (discontinuity of care, lack of information, lack of support).
* Community-based services, when located can be helpful (AS), Birth-to-Three, Salvation Army) as they relate to caring for grandchildren
* Types of support needed include higher stipends (for foster care) help with legal issues, child care services, housing, and mental health services.
* These grandparents report little involvement with the Aging Network. Their contact with social services comes primarily through the child welfare system.

Third, the complexity of the daily lives of these caregivers is such that intervention is required, and requested, to assist them to better manage day-to-day issues they confront in connection with their custodial duties and their pursuits to shore up their own best physical and mental health outcomes. Consonant with this discrete category are the following specific findings:

* Despite the complexities of their daily lives, these grandparents view what they are doing to raise their grandchildren as being very important. Through the day-to-day struggles and challenges, they derive purpose, meaning, and satisfaction to their strained lives.
* Reasons for raising grandchildren are consistent with the literature (parental mental health issues, substance abuse issues, immaturity, child neglect, and family crises) and are fraught with their own complexity given the extent to which these things may impair the grandparent’s relationship with their own child.

**QUESTIONS AND RESPONSES**

Each of the three focus groups responded to a set of judiciously predetermined questions. The first focus group had 10 questions posed to it, but as revisions were made in response to participant comments, it stimulated and influenced the thinking and sharing of the fluid focus group process. Consequently, a core of seven questions was constant across the groups. The fundamental questions were derived from a review of the literature on grandfamilies, enhanced by consideration of gaps in that literature. The following questions were asked of the focus group participants. Their responses and summarized by the Principal and Co- Principal Investigator.

**Question 1:** Think back to when you began caring for your grandchild. What circumstances or event led to it?

Responses:

* Caregiving is due to parental abandonment, CPS intervention, parental drunk driving.
* The grandfather took his two daughters from his daughter and later took two sons, one of whom is 24 and still living with him. Now his granddaughter has had CPS involved in the household because of irresponsible parenting. And a general **inability to cope with life**.
* The child’s **mother’s immaturity** led to **neglect** and the father is an **alcoholic**.
* The mother of the child has **mental health issues** which impair her ability to effectively parent.
* There was a divorce and the court assessed the mother as **incapable** of caring for the child; the father entered the **military.**
* A sibling group of three was because the mother has **mental health issues** (personality disorder) which resulted in child neglect;
* The **mother was arrested** for attempted murder of a child; there was **drug use;** child’s father has an **IQ of 80**
* **Child neglect** and adultery as the reason why the child is in care. The son moved back with parents and got involved with **alcohol/drugs**.
* The grandmother shared that even though her house burned and she lost everything, she wanted to prevent her grandson from going into foster care. The child’s mother has a **drinking problem** so the grandmother took custody to prevent involvement from the “system.”
* Great-grandparents are providing care for her an infant because the mother **works 15-16 hours a day**; the great grandparents want to avoid the child going into foster care.

Although it was anticipated that circumstances leading to the custodial arrangement would likely be negative, the problems that prevent successful parenting (e.g. drug/alcohol abuse, “street life” etc.) could suggest a strain between caregiving grandparents and their child as a result of disparate values. One grandmother started to cry during the focus group interview. When asked by the moderator why she was crying, she said she does not always know why she cries. Possibly there is some level of guilt among the caregivers which causes them to question whether they “successfully” parented their own child or, knowing that they did, having to search for an explanation of why things went so wrong (Baldock, 2007). Understanding the extent to which there may be feelings of any type of guilt they can articulate could suggest a direction for future research. The desire to take a pre-emptive strike and take custody of the children before they were put into non-familial care was a prevalent theme. Overwhelmingly, the grandparents expressed concern that the children have some measure of stability and continuity in their lives (and not are shifted from place to place) and that they feel loved and wanted. Wanting to avoid foster care is delineated as a key reason for grandparenting (USA Today, 20110. Previous research has suggested that grandparents may feel compelled to step into the parenting role when their own child is unable or unwilling. They do so because of a sense of role expectation or duties that they have an obligation to conform to and, to ensure stability (Myadze, 2012).

**Question 2:** Describe your day-to day routine.

Responses:

* A grandmother reported that she gets a **call from school every day** informing her that her grandson’s behavior is a problem.
* **She worries about the children** when they are out of the household because they’re teased at school. One of the children is on medication for **ADHD.** The child tends to either be sleeping or on the computer. These children don’t make friends easily, which is a partial explanation for why they are teased.
* The bus is especially grueling. The schools are not very supportive (in how they monitor such behavior) which creates stress. The grandmother reports that “the schools won’t talk with me.” She copes with stress by handing off kids to the spouse.
* The grandmother is **in counseling** which she finds helpful. She gets **support** from friends and family.
* The spouse serves as a counselor to the other. The grandfather proclaims that sometimes he just has to slow down **– “it never gets easier.”** He reports that sometimes the **kids are manipulative. He fears** that conflicts between the kids in schools might go too far since kids in school now have weapons
* **Day-to-day life** requires a great amount of patience because of all of the frustration that occurs.
* The African-American grandmother recounts that the child is in school during the day but she help with his homework when he gets home. He **questions why his mother is not there** to help him and doesn’t spend more time with him; the child constantly asks about his mother and she runs out of things to say in response to his questioning about the status of his mother.

Much of the aggregate frustration of these grandparents which evokes and provokes stress occurs within the purview of their interaction with the school and the manner in which the dynamics between children in the school play out. Grandparents who are providing custodial care, especially those with a child who have Attention Deficit Disorder, feel that the educational needs of their children are not being met (Raicot, 2003) Because school-age children spend so much of their time in the care of the school system and because of the prominent role of the school in the lives of children, it is reasonable for these caregivers to expect the schools to support them in their attempts to successfully raise their children; instead, they perceive that they encounter resistance and stark insensitivity. The literature reveals that functioning in the school environment, for the child and the caregiver, is influenced by the grandkin family arrangement (Edwards, 1998). Several of the respondents in this study openly shared their frustration, and their fear, that they are not being taken seriously by the school system and that accordingly, they are concerned about the resulting outcomes for their grandchildren. Because of structural changes in African-American family life, and social problems faced by African-Americans, African-American grandmother caregivers are increasing rapidly and African-American children are more likely to live in the home of a grandparent than their White or Latino counterparts. Myadze (2012) notes that rates of African-Americans in West Virginia who raise their grandchildren are disproportionately higher to their numbers in the population. Because of the precipitous drop in two-parent households and poverty, grandmother-headed households among this group will seemingly increase (Kelch-Oliver, 2011; Ruiz, 2008). It does not escape notice that the African-American grandmother was the only one to address the child’s relentless inquiries about his mother. Kelch-Oliver (2011) has found that the risk for psychological, behavioral problems, and learning disabilities of African-American children raised in these households is amplified. The future interventions that the grandchildren will likely require can impact the health of the caregiver.

**Question 3:** On a scale of 1 to 10, with 1 being not at all and 10 being extremely well, how would you rate how well you have taken care of yourself over the past six months?

**Responses:**

* One grandfather rated his health as a “9” because of his ability to cope. He has learned to “think before I speak” to the grandchildren. He has learned to listen.
* Another also rated himself a “9” because he has learned to live a lifestyle that allows him to take care of himself physically and mentally.
* His wife also rates herself a 9. The children also have health issues which means they’re always going to the doctor for something; she has “learned to do one thing at a time.”
* A grandmother who has temporarily suspended the caregiving role rated her health a 5; her husband rated his 8.5 now. When they had their granddaughter one month ago they shared that the ratings would have been 2 and 4.5 respectively. The husband said it is important to “take care of yourself first” even though sometimes there isn’t enough time in the day. His wife said she tries to take a walk each day.
* The most demure of the grandparents reported a 7, revealing that she has accepted the results of the situation and that she relies on her faith. The welcome diversion that her hobbies provide allows her to better contend with the “tug of war” she experiences with her 15-year old granddaughter.
* The 81 year-old great grandmothers said she signed up for a one day wellness workshop sponsored by her insurance company and it was helpful in making her aware of ways she could take better care of herself. Her rating was a 9.

The role of time management and good planning are apparent in coloring their perceptions of their health. Since many of their subsequent comments contradicted or called into question such a high rating, the function of perception cannot be discounted. Further, coping skills that have been acquired either through resignation or through lifestyle artifacts (e.g., prayer, exercise) are noticeable. There is adequate evidence that the role of caregiver and the related circumstances are stressful enough to impact the perception of heath. Other focus group research (Bachay & Buzzi, 2012) also recognized that overwhelmingly, and even contrary to anticipated “common sense,” grandparent caregivers considered themselves to be in good, very good, or excellent health. It is puzzling that the African-American grandmother, who by all objective accounts was in the most dire situation financially and lacking the most formal social support, did not perceive her health to be bad. An African-American respondent in the Ruiz (2008) study took pride in reporting that she did not have any problems, although there were observable social and physical health problems. The role of race and ethnicity in perceptions should be explored.

**Question 4:** Are there concrete things you can identify which suggest that your health is impacted by your caregiving?

**Responses:**

* The great-grandmother is again “parenting” raising great grandchildren. She has had to deal recently with the death of her husband, sister, and nephew but she said she “can’t stop going” because of the childrearing responsibilities. She has heart disease, but otherwise believes she is healthy. Her 50 year-old son that helps. “I get tired but I plan to live to 100 because I have to get these kids raised.”
* A grandmother and a grandfather **developed** high blood pressure because of the demands of providing care at their age.
* A grandmother loses sleep; tries to eat better and exercise and has learned to “accept the child’s parents as they are.” Most importantly, she says she has to “leave it to our maker.”
* A grandfather who was generally patient, became impatient
* The strain that’s put on the marriage (husband not as patient as wife) can make health situations worse.
* The wife’s health is good; the husband’s health is not. There are heart problems that are made worse by the caregiver stress.
* One of the younger grandmothers reports that she is **nervous all the time,** which impacts her health.
* More than half of the grandparents are frustrated at the thought of the children being returned to their previous home and is practically a daily preoccupation.
* The African-American grandmother addressed the cumulative demands of providing child care, attending to the child and filling in for his mom. She feels like **her life is on hold**. She has previously had a heart attack and has had triple by-pass surgery and three **strokes**. Not having her own place with her own things is a challenge which makes her feel stressed. She **lives in her sister’s home** for which she is appreciative but she and the grandchild have to be concerned that it is not their house and because of that they must behave differently.
* The great grandparents face the challenge of **limited activity level** to care for themselves and the child since the great-grandfather had cancer.

The respondents revealed that the reconfigured family constellation and accompanying dynamic was a recipe for stress. Elevated levels of stress that extend from the “grandfamily” arrangement are recognized as a common occurrence (Edwards, 2003). Financial stress is consistently identified as a source of stress in grandfamilies. Inadequate housing is particularly identified as a caregiver burden among African-American grandmothers by Ruiz (2008) and was exemplified in this study. Previous research cited in USA Today (2011) has found that grandparents often worry about two generations of children – their own and their grandchild. This surely adds to their stress. In concert with the stress that comes from inadequate finances, social isolation, role restriction, cramped living quarters, and negotiating service systems, the fear of not being able to raise the child to adulthood can cause additional fear and stress (Myadze, 2012). Considering the mean age of the respondents in this study, that is a likely concern which is difficult to express since it involves the mortality of the caregiver which is difficult for many people to discuss under the best of circumstances. Of course, younger caregivers have their own problems likely related to a conflict between their needs and the needs of the child (Myadze, 2012).

In different ways, many of the grandparents lamented their loss of freedom to devote themselves to what they thought would be the pursuit of their own concerns and pleasures of life during their later years. At the same time, the generativity of the lives associated with the care they were providing spoke volumes to their explicit understanding that they must remain healthy and focused for their “kids.” In an ideal world, caregiving arrangements into which grandparents have entered would at some point lead to reunification between their children and their grandchildren. The realization that extreme interventions are required in order for this to ever become a reality appears to be an undercurrent of the impact on caregiver health.

**Question 5:** What types of social services, if any, are you currently receiving either for yourself or for your grandchild/ren? What type of support do you get?

**Responses:**

* A grandmother reported that her husband is social of **informal social support.** The **formal social support** in the form of case workers is frustrating and splintered because the case workers are in other counties.
* The **system (**CPS, foster care**) is a major frustration.** Being able to get the **Medicaid card** is essential to providing care for their grandchild. The stipend is helpful in buying food or paying utilities.
* Caring for the children is a **financial hardship**. **ASO funds** for transportation are helpful.
* For the grandparent couple, the daughter is a drug informant so several different counties are involved in the lives of the grandchildren.
* **Religion** was identified as a key variable in caregiving for the children. It gives life a sense of purpose. With the **challenges,** the respondents offer that once they get through them it leads to stronger relationships within the family.
* The grandmother reported that her husband is social of **informal social support.** The **formal social support** in the form of case workers is frustrating and splintered because the case workers are in other counties.
* The **kids have learned such bad habits** in their other home environments(e.g. throwing trash on the floor, not being clean, not eating appropriately, not having any parameters; not knowing how to do homework) that these things present **challenges** and they need help in dealing with it.
* This leads to frustration at the thought of the children being returned to their previous home and they want help to keep this from happening.
* A grandfather was adamant that” **no child can come through the foster system or be moved from home to home and not have problems.”** But knowing where to go to get that help is not easy.
* Theyalso expressed frustrationin attempting to get information. They feel like they get referred from one person in the system to another.
* There is discontinuity of care and there is also high turnover rate in caseworkers.
* Several of the grandparents agreed that lack of information about how and where to get help is a problem, but they cope with the frustration by independently using the **internet** to get information. They report that diligence is needed to find what out’s there.
* They all reported that they would appreciate some central repository of information which is easily accessible.
* One couple discussed how the state hasn’t raised the monthly stipend for care since 1992 and the amount they get is too low to properly care for the child.
* A grandmother was referred to the welfare department (child welfare system); she has **problems finding babysitting;** there’s always a new person at DHHR which frustrates her. “We never found anything, except for BTT.” Most programs have income requirements.
* Her husband drew attention to problems finding help with legal issues; information is not all in one place; not everyone can use the Internet.
* It was shared that that CWLA (Relative as Parents Program Training) is good. Generation United is also a **source of support**. The NCOA provides a “Benefits Check-Up.”
* A set of grandparents identified DHHR, Coventry House, and Salvation Army as sources of support and care. They all replied that the **system gives them the run-around** when attempting to get information about services. The couple reinforced the importance of the **church family** as a source of support and strength. The **inner peace** they have in knowing that they are doing good is an internal resource.
* The schools are not very supportive, which creates stress. A grandmother reports that “the schools won’t talk with me.”

Although there is a wealth of resolve demonstrated by the grandparents in this study, an inability to find temporary relief from the caregiving role can threaten that resolve. Developing long-term strategies to nurture these families and promote family stability is both a practical and a policy issue. The Family Strengthening Center (2007) has drawn attention to the latter. Keeping their grandchildren in school is an evident immediate and long-term goal of the grandparents which has been borne out in other research (Murphy, 2008). Legal rights to support grandfamily efforts to adopt grandchildren and to be their advocates and to face other legal and policy dilemmas (Letiecq, 2008) is found in this research, and in other research (Balcort, 2007; Racicot, 2003) to be a common theme. The Administration on Aging (AoA) manages the National Family Caregiver Support Program (NFCSP) which is the main support for grandparents who are at least 55 years old and may need a respite from caring for a child under the age of 18 (Family Strengthening Policy Center, 2007). Only one respondent had concrete information on this form of temporary relief while another was hoping that she would be able to get this type of information from the session. Moreover, the lower limit age of 46 for our respondents is not out of the ordinary for contemporary grandparents which raises issues about NFCSP and other resources that are age-driven.

Practically all of the grandparents identified an experience of being turfed as they solicited services and support. The power of informal social support was identified as a starting point for information as well as a buffer to stress. One form of informal social support is a spouse. Data on West Virginia custodial grandparents reveal that the state stands out from surrounding states in that it has the highest estimated percentage of co-resident grandfathers. However, one should not assume appreciably higher income levels because of this factor (Myadze, 2012). All of the grandparents mentioned that it is expensive to raise a child and if it is the preference of the state to have children placed in kinship care, there must be a re-evaluation of the stipend. They affirmed that the caseworkers are good but because of their high caseloads they are greatly overwhelmed. The system (CPS, foster care) is a major frustration. Sands, Goldberg, and Thornton (2005) investigated factors associated with positive well-being of grandparents who are caring for their grandchildren. They found that social workers can provide valuable assistance to grandparent caregivers by lowering their perception of stress and by improving their connections to informal supports and community resources. The void in knowledge for most caregivers in this study is more oriented toward the community resources. The behavioral and emotional problems of children which are a common consequence of sudden or multiple transitions while they are young (Family Strengthening Policy Center, 2007) was identified in this group of grandparents and is an area in which assistance is needed and requested. As Letiecq (2008) points out, there is fear of the welfare system on the part of many grandparents, perhaps because of the lack of a definitive kinship care navigation system. While none of these grandparents used the word “fear” to describe their clashes with the welfare system, the sentiments they articulated regarding their anxiety can be interpreted as tantamount to fear.

**Question 6:** What one thing would you change about your caregiving if you were able to change anything at all?

**Responses:**

* One grandfather said he would like to have more information on health issues, especially mental health, since his daughter for whose children he provides care, has bi-polar disorder.
* The grandmother (his wife) said she would like help with the importance of medication compliance to manage children’s behavior.
* The same grandfather revealed that he would like information on the genetic explanation for mental health issues. He’s worried that there is a **genetic link** and is concerned about the implications of such a link.
* A major concern of these grandparents is dealing with children who themselves have special needs; they would like to have information about how to deal with these issues and to how plan for the future with the issues that they face.

There was little appreciable demarcation between the responses to questions 6 and 7. The researchers conclude that this likely represents the inextricable link between the mental health issues of their children and grandchildren and how they can work within the boundaries of profound constraints to serve children in their care. Grandparents frequently feel tired and worry about their ability to keep going to provide care of their grandchildren (Baldock, 2007) but are committed to doing so.

**Question 7:** How would you feel about a 6-week free workshop on how to manage your health?

**Responses:**

* A soft-spoken grandmother said being equipped with communication skills to learn what to say and what not to say would be helpful. She claimed that “every day is a **psychology test** living with a 15 year old.”
* Developing parenting skills and learning more about child development would be helpful.
* Respondents suggested a need for help to address mental health concerns, family dynamics, information on managing family relationships, and dealing with anger issues.
* A grandmother said a workshop on **skill building** would be beneficial. She loves to cook and would like to know how to do something with that.
* A workshop that teaches **basic education and religion** would be worthwhile. A workshop to **better manage health issues** and impart **ways to cope with stress** would be helpful.
* A workshop on diabetes and how to manage that and other diseases such as HBP.
* One grandfather said he would like to have more information on mental health issues, especially mental health since his daughter for whose children he provides care, has bi-polar disorder.
* A grandmother of that couple said she would like help with the importance of medication compliance to manage children’s behavior.
* The grandfather spouse revealed that he would like information on the genetic explanation for mental health issues. He’s worried that there is a **genetic link**. They all said they would attend a **6-week workshop** on understanding mental health issues. The husband and wife would not attend a workshop on understanding mental health issues.

Concern about a possible genetic link strongly suggests a possible stigma, guilt, or sense of shame that many grandparents feel about the situation(s) that prompted their caregiving and whether they could have prevented it (Baldock, 2007). A major concern of these grandparents is identifying sources of support for children who themselves have special needs (Murphy, 2008; Racicot, 2003). They unanimously shared a compelling need to have information that will equip them to respond to these issues and to plan for the future with the issues that they face. Many grandparents lack confidence with computers and other forms of technology that allow them to access information (Baldock, 2007) on a variety of topics related to their family dynamic.

**CONCLUSION:**

Grandparents who are raising their grandchildren have more physical disability and depression than their peers who are not raising grandchildren (USA Today, 20110. Anxiety and depression is correlated with inconsistent parenting (Baldock, 2007) so the need to strengthen grandfamilies is paramount. Grandparents can develop strengths when they can alter their dreams and embrace a perspective that allows them to manage their stress (Strom & Strom, 2011). They can benefit from assistance of this type. In other studies, grandmothers who are raising their grandchildren have shown more stress, intra-family strain, and perceived problems in family functioning. They have been found to have the worst physical health and more depressive symptoms and experienced the least reward and reported the least subjective support (Musil, Gordon, Warner, and Zauszniewski, Jaclene, Standing, and Wykle, 2011). The need to prevent clinical symptoms in both caregiver groups is imperative; however, based on findings from previous research and what was gleaned from this study, a variety of intervention modalities is required to ensure that the health of the grandmother caregiver is not threatened by their heightened involvement in caregiving compared to grandfathers (Myadze, 2012).

There are common feelings of loss, perhaps associated with the loss of their own child who is not there to parent, coupled with loss of aspects of their traditional grandparent role caused by dynamics borne out of the grandchild’s response to parental “loss” (USA Today, 20110). This was culled out from this research. It is important to ensure that information is not fractionalized and is easily accessible to caregiving grandparents. Further research could address the reciprocity of well-being between grandparents and their grandchildren as a feature of grandparental health and well-being as Strong, et. al. (2011) have done in their investigation of trauma associated with raiding children in grandfamilies. Since grandparents are so vested in positive outcomes for their grandchildren, research to identify how children respond to parental loss, disruption (Kelch-Oliver, 2011) and other sociocultural variables can improve outcomes for grandparents. Interventions to promote resourcefulness of grandfamilies can mitigate the impact of their stress since this is more than just a moderate need (Zauszniewski, Jaclene, Au, Musil, & Carol, 2012). Assisting grandfamilies transcend any stigma of substance abuse, leading to care, that could influence attitudes of a range of neighbors, school officials, etc. (Baldock, 2007) can be instructive

**Works Cited**

Bachay, J.B. & Buzzi, B.M. (2012). When grandma and grandpa become mom and dad: Engaging gandfamilies in clinical practice. Kriminologija I Socijaina Integracija, Vol 20. (No 1) Spranj 2012.

Baldock, E. (2007). Grandparents raising grandchildren because of alcohol and other drug issues. Family Matters (No. 76).

Edwards, O.W. (2003). Living with grandma: A grandfamily study. School Psychology International. Vol 24. (No 2).

Edwards,O.W., (1998). Grandfamilies: Grandchildren raised by grandparents. Impact on students and school services. January 1, 1998. ProQuest ETD Collection for FIU. Paper AAI9835705

http://digitalcommons.fiu.edu/dissertations/AAI9835705.

Edwards, O.W (1998) Helping grandkin - grandchildren raised by grandparents: Expanding psychology in the schools. Psychology in the Schools Vol 35, Issue 2.

Edwards, O.W. (2003). Living with grandma. School Psychology International. May 2003 (Vol 24) Issue 2.

Gottlieb, A.S, Silverstein, N.M., Canhoto-Bruner, L., & Montgomery, S. (2000). Life at grandfamilies house: The first six months. Gerontology Institute Publications. Paper 23. http:// scholarworks.umb.edu/gerontologyinstitute\_pubs/23.

<http://en.wikipedia.org/wik/Race> and ethnicity in the United Sates Census (2010).

Kelch-Oliver, K., (2011). African-American grandchildren raised in grandparent headed families: An exploratory study. Family Journal (October 2011) Vol. 19 Issue 4.

Letiecq, B.L. (2008). “We have no rights, we get no help.” Journal of Family Issues. Vol 29 (No 8). 995-1012.

Myadze, T.L. (2012). Characteristics of grandparents residing with dependent grandchildren in West Virginia and four comparison states that practically overlap northern Appalachia. American Journal of Contemporary Research. Vol. 2 No. 2, February 2012.

Murphy, A. (2008). Grandparents who care for their grandchildren. Undergraduate Review, 4, 13-16. http://vcbridgew.edu./undergrad\_rev/vol4/iss1/7.

Musil, C.M., Gordon, N.L, Warner, C.B., Zausniewski, J.A., Standing, T., & Wykle, M. (2011). Grandmothers and caregiving to grandchildren: continuity, change, and outcomes over 24 months. Gerontologist. (February 2011). Vol 51, Issue 1, p 86-100.

Works Cited

Racicot, L. (2003). Understanding he needs and issues of grandfamilies: A survey of grandparents raising grandchildren . A pilot study. Paper presented at the Biennial Meeting of the society for research on child development (April, 2003). <http://www.eric.ed.gov/ERICwebPortal/search/detailmini.jsp?_nfpb=truc&_&ERICxtSe>...

Ruiz, D.S. (2008). The changing roles of African-American grandmothers raising grandchildren: an exploratory study in the piedmont region of North Carolina. The Western Journal of Black Studies, Vol 32, No. 1.

Sands, R.G., Goldberg, G.R. & Thornton, P.L. (2005). Factors associated with the positive well-being of grandparents caring for their grandchildren. Journal of Gerontology in Social Work. Vol 45 (4). 65-82.

Strengthening grandfamilies through respite care (2007). Policy Brief No. 20. (January 2007).

Strom, P.S.& Robert, D. (2011). Grandparent education; Raising grandchildren. Educational Gerontology. (October 2011). Vol. 37, Issue 10, p. 910-923

Strong, D.D., Bean, R.A., & Leslie, L. (2011). Trauma, attachment, and family therapy with grandfamilies: A model for treatment. Children and Youth Service Review, January 2010. Vol. 32 Issue 1, p. 44-50.

USA Today (7/26/2011). More kids today living in grandfamilies.

Zauszniewski, J.A., Au, T.Y., & Musil, C.M. ((2012). Resourcefulness training for grandparents raising grandchildren: Is there a need? Issue in Mental Health Nursing (October 2012) Vol 33, Issue 10, p. 680-686.

APPENDIX A

(Help Yourself Chronic Disease Self-Management Program Survey)

APPENDIX B

(The Caregiver Burden Inventory)