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CAREGIVERS PERCEPTIONS OF PERMANENCY PLANNING
FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Joanne Sue Claytor


June 2000

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FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

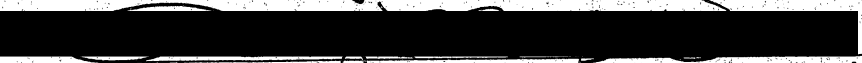
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Approved by:


Dr. Rosemary McCaslin, Research Advisor
Social Work

6/13/00
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ABSTRACT

The purpose of this study was to provide qualitative, narrative data on primary caregivers' views concerning future planning for adults with developmental disabilities. This research explored their perceptions of stress and family functioning pertaining to the planning process. It is expected that the results from this study will help to bring about an increase in awareness of the importance of permanency planning by families and to assist service providers in their efforts to discuss this process with families of adults with developmental disabilities.

ACKNOWLEDGMENTS

I would like to acknowledge all the parents and siblings of adult individuals with developmental disabilities I've had the pleasure to know and work with over the years.

Heartfelt thanks to my husband, Barry, and my daughters, Amanda and Adrienne, who have been very patient and supportive of me over the last two years. Thank you for believing in me and helping me accomplish my goals.

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PROBLEM STATEMENT

When parents of children with developmental disabilities enter old age, they face a multitude of challenges associated with the needs of their adult children (Cook and Cohler, 1986). Research has documented the stresses and gratifications associated with this "perpetual parenthood" (Grant, 1988; Greenberg, Seltzer, and Greenly, 1993). Many of these parents worry about how they are going to continue to care for their adult children as their own health fails and who will care for their son or daughter after they are gone.

The increasing attention to residential transitions from the homes of aging caretakers to out-of-home placements, reflects a broad recognition of the aging of the American population and the accompanying aging of family caretakers (Freedman, Krauss, & Seltzer, 1997; Heller & Factor, 1991). Over one-quarter of those individuals with mental retardation living in family settings (excluding living with a spouse and in one's own residence) reside in households headed by a family member 60 years of age or older. Another 35% live in the households of middle-age caretakers, for whom transition issues are near term considerations (Fujiura, 1998).

Due to cutbacks in funding for institutional

facilities, there has been an increasing prevalence of adult persons with mental retardation remaining with their natural families most of their adult lives (Seltzer & Krauss, 1989). The nation's long-term care residential systems serve only a small proportion of all persons with mental retardation and closely related developmental disabilities. The formal out-of-home residential care system in 1991 supported approximately 338,000 individuals (Braddock, 1995) of the estimated 2.97 million persons with mental retardation. The vast majority were supported in family residences by parents, relative, or other benefactors.

These high numbers may be attributed to the fact that permanency planning for adults with a developmental disability is a complex process. Smith, Tobin, and Fullmer (1995) state that residential planning is the most emotionally laden component of permanency planning because older parents must acknowledge that their sons or daughters may some day not reside in their life-long home" (p. 487). In most families with adult children who have mental retardation, this issue is not addressed until there is a crisis, which motivates family members to begin to consider alternative living arrangements. Due to delayed planning, service coordinators spend an enormous amount of time trying

to make emergency placements, families face long waiting lists, and too often, few satisfactory options are found (Heller & Factor, 1991; Janicke, Otis, Puccio, Rettig, & Jacobson, 1985).

Careful planning for the future or permanency planning, that considers the entire family's needs and concerns is likely to be very helpful. Siblings are important sources of support for adult-children with mental retardation and can assist in the process of future planning (Seltzer, Begun, Seltzer, & Krauss, 1991). Sibling relationships are often important, extensive and lifelong (Seltzer et al., 1991). In families with adult-children with mental retardation, siblings can act as parental surrogates and caretakers (Lobato, 1983).

Little is known about how families plan for the future and make decisions concerning the future care of adult-children with mental retardation. There has been even less research focused on the siblings of these adult-children and sibling involvement in parental decisions concerning the future planning and placement process (Blacher, 1990). Previous research on siblings has emphasized the amount of sibling involvement at adulthood, rather than the sibling's opinions and expectations of caregiving. In addition to this, prior research has studied the factors affecting

parental decisions to place adult-children with mental retardation in out-of-the-home placements in group homes or institutional arrangements, rather than having them live with siblings and other family members (Heller & Factor, 1988; Sherman, 1988; Tausig, 1985).

While there is a growing amount of literature (Seltzer & Krauss, 1994) on the circumstances of parents who provide lifelong care to a family member with a disability, much less is known about the consequences for the adult siblings in these families. When parents are no longer able to care for the family member who has a disability, the responsibility of care may rest on the sibling (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). The role of siblings (Krauss, Seltzer, Gordon, & Friedman, 1996) is an important theme not addressed in current research. Given the size of the baby boom cohort and the transfer of resources and family responsibilities from one generation to the next, sibling-based family support is an active issue of potential importance that deserves additional research (Fujiura, 1998).

Due to shortages in state and federal funding and an increased demand for services, the social service system has been unable to help families sufficiently in caring for their adult-children with mental retardation. Long-term and

traditional services, such as group homes and other community facilities, have not been able to meet the needs of adults with mental retardation (Davis, 1997). It is expected that the results from this study will help to bring an increased awareness of the importance of permanency planning by families and to assist service providers in their efforts to improve future planning and caregiving arrangements for families of individuals with mental retardation.

The purpose of this exploratory study was to learn more about caregivers' views concerning future planning, and their perceptions of stress and family functioning pertaining to this planning process.

LITERATURE REVIEW

The medical and technological advances over the past 20 years have resulted in the expectation that large numbers of children with severe mental retardation will not only survive childhood, but will live to adulthood and old age (Janicki & Wisniewski, 1985). While it is not known how long people with mental retardation will live, it is estimated that more than 40 percent of them will survive to age 60.

This is an important issue to consider due to the fact that the number of people with mental retardation aged 60

and older is projected to double to Krauss, 1997). The aging of this population plus the extreme shortage of residential placements means that our society will see many more two-generation households of older people with developmental disabilities being cared for by their very old parents.

Increases in families unmet needs for formal supports are associated with increased caregiving burden and a greater need for out-of-home placement. Older families, especially those who have kept an adult family member at home over the years, are greatly disturbed by the waiting lists for services (Heller & Factor, 1993). These parents experience concerns and worries about their child's future when they, the parents, are no longer able to provide the needed care or supervision.

Meyer, Vadasy and Fewell (1985) write that although siblings frequently have a life-long need for information about their siblings' disability or illness and its implications, siblings have far fewer opportunities for obtaining information than their parents do. When brothers or sisters go along with their parents to a clinic visit or an educational meeting for the sibling, their questions, thoughts or opinions are rarely solicited. Seltzer, Greenberg, Krauss, Gordon, & Judge, (1997) compared siblings

of adults with mental retardation with siblings of adults with mental illness with respect to the pervasiveness of the impact of the brother or sister on the sibling's life; the closeness of their current relationship and the frequency of contact with the brother or sister with the disability; and the factors related to the sibling's level of psychological well-being. Results of this study found that siblings of adults with mental retardation were more likely to perceive that their brother or sister has a pervasive influence on their life decisions and viewed this experience as mostly positive. This population of siblings had closer relationships with their brother or sister who has mental retardation compared to those siblings whose brother or sister has a severe mental illness.

One of the gaps found in the literature was the role adult siblings have in families of aging parents who are caring for adult children with developmental disabilities. There were approximately 47,000 persons with developmental disabilities who were identified as living with a sibling in a demographic study done by Fujiura (1998). He reported that this is a significant undercount due to the difficulties in linking sibling relationships to other persons in the household. These relationships were only linked to the household head and may have excluded siblings

or spouses or other household members. The studies done have not discussed the value of siblings as a means of support to their aging parents. Very little is known about how their relationships with the sibling who has mental retardation will affect future caregiving responsibilities.

Also missing in the studies reviewed was the impact cultural values and beliefs had on the aging parents caring for their adult family member with developmental disabilities. Some research found that socioeconomic factors had an impact on the level of future planning a family had done. There is good evidence that African American caregivers use fewer formal services and possess less knowledge about specific diseases and disorders when compared with their White counterparts (Ballard, Nash, Raiform, & Darrell, 1993). Most researchers attribute this trend not to a lack of need, but rather, to existing barriers to service use. Problems with transportation, work schedules, and stigma have combined in such a way as to marginalize African Americans and other minority members from receiving Abest practices services (Pruchno, Patrick, Burant, 1996).

Previous research regarding out-of-home placement, has focused on Anglo, middle-class populations. By the turn of the century, Latinos will be the largest minority group in

the United States (Chan, 1991). It is critical that service delivery decisions be based on culturally appropriate information. Additional research needs to be done to better understand the needs of families with diverse cultures and beliefs.

Studies in California have shown that the placement rate for Latino individuals who have mental retardation at all ages and levels of ability are lower than for Anglo or African American groups. Using a family-ecology perspective (Crnic, Friedrich, & Greenberg, 1983), potential placements in Latino families might be affected by parents relationship to community agencies and professionals, language barriers, uncertain immigrant status, and level of acculturation.

There is a need for research that looks at the relationship between siblings with and without disabilities in Latino families, both before and after placement. These sibling's language skills and level of acculturation often exceed those of their parents. Therefore, they may play a more crucial role in placement involvement and interaction with service delivery systems than do Anglo siblings.

There were conflicting findings regarding the role of formal and informal support systems in families' future plans. Heller and Factor (1991, 1993) found that greater use of formal supports and high levels of unmet service

needs corresponded with family preference for out-of-home placement requests and decisions. It was also found that greater service use and help from other relatives were significant predictors of stage of future planning in families. Mothers of adults with mental retardation reported having considerably large support networks and they perceived their family environment to be significantly supportive.

Other issues associated with support systems of families with adult children with mental retardation focus on negative interactions in family life (e.g. family conflict), which amplifies the experience of stress for aging parents who are caring for their adult children with developmental disabilities. Greenberg, Seltzer, & Greenly (1993) reported that most caregiving research has painted a portrait of the elderly as frail and dependent, with the flow of family assistance traveling up the generational ladder. However, their study approached the topic from a strengths perspective. Their findings suggest that elderly parents derived gratification in their relationships with their adult children with mental retardation and they viewed this as a positive experience. These parents served as the mainstay of their child's life, providing both instrumental assistance and support to them. It's important that the

social service field not lose sight of the fact that the majority of older persons are healthy and independent and that they are more likely to be a force that stabilizes the family rather than taking away from the integrity of the family.

Some of the limitations found in the research is that these studies rarely asked siblings and parents to report separately on their opinions. Researchers have relied more heavily on the parents' views of sibling behaviors and attitudes versus having the siblings voice their own views (e.g., Seltzer et. al., 1991). Siblings who participated in the studies were selected by their mothers as being the most involved with their brother or sister with mental retardation, which could bias the results of the study. These siblings have a plan about whether or not they anticipated living together or apart from their brother or sister.

Generalizability is limited to this group. Findings obtained from such studies are likely to have analyses based entirely on the siblings' projections of future roles, but these plans may shift in response to changes in the circumstances of parents, siblings, the adult with mental retardation, and the service delivery system. In some families, there was only one sibling to the person with

developmental disabilities, therefore, it is difficult to generalize the findings to parents who had at least two siblings. Another population that was not in these samples is siblings who have infrequent or irregular contact with their siblings with mental retardation or those from highly stressed or unhealthy families. It seems that most of the parents and siblings were interested in the studies and from a healthy family.

There are many theoretical perspectives that have guided previous research regarding siblings and families of children with mental retardation. They are the stress process model (Pearlin, Mullan, Semple, Skaff, 1990), the ecological theory using a case management model, family systems theory, (Minuchin, 1985) and the model of family stress and coping (Crnic, Friedrich, & Greenberg, 1983). This study used the family systems theory for conceptualizing the stress of families that include a child with mental retardation. The ecological perspective recognizes the importance of examining the needs of families in relationship to their culture and community, their ability to get needed goods and services and support systems. This theory lends itself well to this research because it views the individual, family, community and environment as interconnected into a whole system. Problems

arise out of the inability of families to effectively adapt to internal and external stressors due to the lack of resources. These resources would include familial, financial, legal, as well as social services.

This study was built upon the previously discussed research, by continuing to address the stressors aging caregivers face and how this affects future planning with their adult-child with mental retardation. It explored the special role siblings play in this process and expanded on the relationships they have with their brother or sister with developmental disabilities. This research used a strengths perspective to study this important topic.

METHOD

This purpose of this study was to explore and describe issues that primary caregivers (parents, siblings or other relatives) face concerning future planning for adults with mental retardation. The study employed a qualitative research design utilizing face-to-face interviews.

The individuals who participated in this study were caregivers or adult siblings of adults with mental retardation. Study participants were recruited from various parent-to-parent organizations/associations and social service agencies that serve adults with developmental disabilities using a snowball sample. The study

participants were selected on the basis of age, place of residence, and ethnicity. All participants were 18 years of age and older and identified as being the caregiver or sibling of an individual who has developmental disabilities.

The study's author contacted participants by phone to set up an interview date and location convenient for them.

Three of the thirteen interviews were completed over the telephone and the remainder were face-to-face interviews conducted by the author in each participant's home.

There are six questions the author asked each interviewee in order to explore caregivers' perceptions and views of permanency planning for individuals with mental retardation. 1) Has your family contemplated long-term planning for your adult child with developmental disabilities?). 2) If yes, what discussions have taken place between family members (parents and adult siblings?). 3) In the event you are no longer able to care for your son/daughter or sibling who has mental retardation, what type of living arrangements would you like to see made for him/her?). 4) What role do you, as the parent, perceive your son/daughter without mental retardation to assume when you are no longer able to provide care for your adult child with mental retardation?). 5) How do you perceive your role in the event your parents are no longer able to provide care

for your sibling with mental retardation?). 6) What information has been shared amongst family members regarding the types of social services and agencies involved with the adult with mental retardation?).

The participants were asked to read and sign an informed consent before the interview (Appendix A). They were asked the above mentioned exploratory type questions regarding permanency planning and their perceptions surrounding this process.

Each participant was also asked some demographic questions: age of parent or sibling; gender and age of the adult with mental retardation and their current living arrangement; and the nature of the disability.

A Debriefing Statement (Appendix B) was given to each of the study's participants who specified resources for support or in the event that the participant should be caused any stress or psychological discomfort due to the interview.

RESULTS

Thirteen participants were interviewed. Eight of these participants were parents and five were adult siblings of individuals with mental retardation. The participants who were parents included: two married couples, two mothers who were married, and one single mother, and one widow. All of

the sibling participants were female; three of them were single and two were married. Three of the five siblings had parents who also participated in this study. Twelve of the adults with mental retardation lived at his or her parents' residence. Only one male adult with mental retardation lived in a group-home setting. The ages of the parents interviewed ranged from 50 to 88 years old and the siblings interviewed ranged in ages from 29 to 60 years old. The adults with mental retardation ranged from 19 years old to 59 years old. Eleven of the participants identified as Caucasian and two as Latino.

Parents and Siblings Discussions of Permanency Planning

Parents and siblings were asked whether or not they had discussed alternative living arrangements for their family members with mental retardation in the event the current caregiver could no longer provide for their care. From the thirteen parents and siblings interviewed, one couple responded that they had never thought about it nor had they discussed this with their adult children. The father stated, "We adopted M. after our daughters left home and were starting families of their own. If she had been a biological sibling, we would have expected the older sisters to assist us more." He further replied, "They could say, 'you knew what you were getting into when you adopted her.'"

His wife went on to say, "I don't know what we'll do when he has to go in for his cancer surgery." Both parents were concerned about this lack of support, but continued to be reluctant about asking their adult children for assistance.

Five of the eight parents interviewed said they did not want to burden their other children with the responsibility of caring for their sibling with mental retardation. None of these parents had made formal plans for the adult siblings to assume caregiving responsibilities when the parents were no longer able to do so. The remaining three parents believed that even though it will be difficult for the siblings, they viewed this more as a responsibility to another family member.

One mother said, "Family is not a burden." While she has taught her children that family takes care of their own, she has told her adult children that "they have a right to say no to taking over the caregiving responsibilities when I'm no longer able to do so."

Out of the five adult siblings interviewed, all of them reported that they are willing to take over caregiving responsibilities when their parents are no longer agreed to this arrangement, only one of them reported that her parents have taken legal action to add her name as her brother's conservator in the event that

they are no longer capable of doing this. This sibling stated, "This is a great deal of responsibility and sometimes I feel overwhelmed by the magnitude of what it entails." According to another sibling, "it doesn't matter what my mom wants, I plan to take care of my sister when my mom isn't able to anymore."

Future Living Arrangements

A Latino mother described her husband's plan for permanency planning when he told her, "If you were not around to take care of the boys, I would have them placed out-of-home right away." Therefore, she "prays to God each day to keep her healthy and alive" in order to care for her three children with disabilities.

Six of the eight parents indicated that while they would like their non-disabled adult children to take over the caregiving responsibilities for the adult child with mental retardation, none of them had put this into writing.

Four parents had set up a trust fund for their adult children with mental retardation so that they are not a financial burden to the sibling they are living with. "I have arranged to have funds available to my daughter in order for her to fly down here to see her brother if he is not living with her."

Two mothers said, "My daughter says she'll take care of

her brother, but I don't think she can handle it." Another mother commented, "I would never come out and ask my daughter to take in her three siblings, but I am relieved that she has offered to do so."

More than half of the parents stated they foresee the need for someone outside the family to come in to help with the burdens of caring for the individual with mental retardation. This seemed to help them come to grips with the tremendous responsibility their non-disabled adult children are willing to take on in caring for their sibling with mental retardation.

Almost all of the siblings reported having some awareness of the services being provided to their siblings with mental retardation, but most parents had not included them in this information loop. Two siblings who have been more involved in this area expressed a dislike of the Regional Center system. One of these siblings has actively advocated on behalf of her sister whenever there is an issue regarding services from Regional Center (RC) or In Home Supportive Services (IHSS). "Mom tries to make sure I'm there whenever she has to deal with staff from either of these agencies." "I get disgusted when service providers say my sister can't benefit from their services or that she doesn't

qualify because of her behaviors."

There were other findings in this study that were not found in previous research. The sibling of the only adult with mental retardation who is not living with his parents said, "parents who have their life and whole world focused on the adult child with mental retardation are less likely to have this child live away from them. Their whole identity and being is centered around this child. This is how they find meaning and purpose in life." One divorced mother demonstrated just how enmeshed a parent can become with a child who has severe disabilities. She openly stated, "My life revolves around M. I don't date and I don't have any friends to speak of. Who wants a 50-year-old woman with a paraplegic son? I can't separate from M., he's my Siamese Twin. Wherever I go, he goes too."

The older sister of a severely disabled young woman said, "One reason my mom has never placed L. in out-of-home placement is that she has become accustomed to the income she receives from Supplemental Security Income (SSI) and In Home Supportive Services (IHSS) for keeping my sister in the family home." This sibling referred to this as disability welfare and said that this has encouraged and supported her divorced mother in not seeking gainful employment outside the home. Her mother's main source of income is from the

SSI and IHSS she receives on her daughter's behalf. While not often addressed in the literature, this is an important and real issue in the lives of families caring for an adult with mental retardation.

DISCUSSION

The present study has limitations, which include its reliance on primarily Caucasian non-Latino sample and the potential that a volunteer sample might not be representative of the population of aging parents of persons with mental retardation.

There are other limitations to the study's design that should be considered in interpreting the findings. Most participants were connected in some way with a social service system. The findings are not generalizable to siblings who have infrequent or irregular contact with their siblings with mental retardation or highly stressed or unhealthy families. All of the siblings were female which made the sample less diverse.

This was a study of predominately Caucasian, middle-class families. The results should subsequently not be generalized to families in other cultural backgrounds and socioeconomic status because previous research indicates that ethnicity is associated with different patterns of family caregiving and sibling relationships (Heller &

Factor, 1988). More attention needs to be directed to understanding how culture influences variations in caregiving and permanency planning for persons with mental retardation.

In this exploratory study, data were assessed regarding caregivers' perceptions of permanency planning. The majority of siblings and parents believed that the families should be responsible on a long-term basis for the care of family members with mental retardation. Most siblings reported that they were willing to assume future caregiving responsibilities for their brothers/sisters with mental retardation. However, parents were reluctant to have them take on caregiving. Previous research has also documented that female, rather than male, siblings are more likely to assume the caregiving role (Edmundson, 1985) and are more often chosen by parents for this responsibility (Coward & Dwyer, 1990). The fact that all of the siblings in this research were female was consistent with this finding.

All but one of the caregivers in this study were caring for his/her adult child with mental retardation. These results were consistent with previous research suggesting that as this population grows older and residential placements are scarce, that many more older people with developmental disabilities would be cared for by their very

old parents (Essex, Seltzer, & Krauss, 1997).

When siblings did attend an educational meeting for their brother or sister with mental retardation, their questions, thoughts or opinions were rarely solicited. Even when it is known that these siblings will eventually take over the caregiving responsibilities, they still had far fewer opportunities for obtaining information than their parents did. Meyer, Vadasy and Fewell (1985) have reported this in previous research.

Due to shortages in state and federal funding and an increased demand for services, the social service system has been unable to adequately assist families in caring for their adult children with mental retardation. Although siblings may be willing to take on caregiving roles and responsibilities, they have generally been an untapped resource.

Services for those with mental retardation have not traditionally used or included siblings, nor have they been designed to accommodate the increased life span of their adult clients. As families age, service systems could offer integrated, multidimensional family-services, such as in-home and out-of-home respite care, accessible recreational programs, self-advocacy programs for the adults with mental retardation, as well as future and estate planning. It is

also important for family members to have access to mental health services and professionals to help them deal with the issues of caring for adult child with mental retardation. This will help to alleviate family distress and can serve to gradually increase the independence of family members with mental retardation and prepare them for the future transition of being separated from their parents.

Appendix A: INFORMED CONSENT FORM

CONSENT TO PARTICIPATE IN RESEARCH

You have been asked to participate in a research study conducted by Joanne Claytor under the direction of Dr. Rosemary McCaslin, from the Department of Social Work at California State University, San Bernardino. The results of this study will contribute to her research project. You were selected as a possible participant in this study because you are a caregiver or sibling of an adult with developmental disabilities. Your participation in this study is voluntary.

The purpose of this study is to provide information on primary caregivers', family members' and possible future caregivers' views concerning future planning for adults with developmental disabilities.

If you volunteer to participate in this study, you will have a face-to-face interview at a time and place of your preference. The interview will take about 60 minutes. During the interview, you will be asked about the permanency planning you have done in regards to the adult with developmental disabilities for which you are the caregiver.

You have the right to not answer any of the questions you feel uncomfortable with and may stop the interview at any point during the process.

Any information obtained in connection with this study will remain confidential.

Your participation is VOLUNTARY. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without penalty.

If you have any questions or concerns about this study, please feel free to contact Dr. Rosemary McCaslin at CSUSB at (909) 880-5500.

By my mark below, I acknowledge that I have been informed of and understand the nature of the study. I acknowledge that I am at least 18 years of age.

Please sign with a check or X _____ Date _____

Appendix B: DEBRIEFING STATEMENT

DEBRIEFING STATEMENT

Thank you for participating in the study examining caregivers views on permanency planning for adults with developmental disabilities.

If your participation in this research raised any issues you would like to discuss further, there are resources available for you to talk with someone. The following is a listing of resources available to you.

If you would like more information or the results of the study, please contact Dr. Rosemary McCaslin, Department of Social Work, California State University, San Bernardino at (909) 880-5500.

Family Service Association
3634 Elizabeth Street
Riverside, CA 92507
(909) 686-3706

Mid-County Mental Health- Perris Office
2688 North Perris Blvd., Suites L7-L11
Perris, CA 92571
(909) 657-0626

Youth Service Center - Moreno Valley Office
6296 Rivercrest Rd., Suite B.
Moreno Valley, CA 92553
(909) 683-5193

San Bernardino County Mental Health Department
(909) 387-7171

West End Family Counseling
855 N. Euclid Ave.
Ontario, CA 91762
(909) 983-2020

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