

Appendix C: Interview Codebook	
Topic 1: Caregiver Decision Making	
Code Name	Code Description and Questions
Care decision conflicts	Has there been challenges or conflicts with making care decisions for x?
Care decision employment and schedules	How were care decisions effected by the employment and work schedules of those caring for x?
Care decision physical safety	How were care decisions effected by the consideration of physical safety for x?
Care decision website	Did the respondent use websites to aid in making care decisions for x?
Care decision-family helpers	Have family members of x besides the respondent helped with any care decisions?
Care decision-medical or physician helpers	Have medical professionals helped with any care decisions regarding x?
Care decision-other social network helpers	Have people in the respondent and x's social network including friends, neighbors, church community, etc. helped with any care decisions regarding x?
Care decision-social work helpers	Have social work professionals helped with any care decisions regarding x?
Care options available or eligible for	Care options that are available to x that they are eligible for
Caregiver support groups online or in-person	Has the respondent participated in caregiving support groups?
COVID-19 and decision making	Discussion of decision making within the context of COVID-19
Evaluation of quality of care	How did the respondent evaluate the quality of care when making care decisions for x? How did the evaluation of quality-of-care effect care decisions for x
HCBS consideration	Has the respondent considered home and community-based care options such as a home health aide, meals on wheels, home nursing care, etc.?
Nursing home consideration	Has the respondent considered nursing care for x?

Other care options considered	Has the respondent considered other care options such as adult day care, senior activities, church activities, etc.?
Tipping point	Discussion of an event that caused the change in type or extent of care
Topic 2: State Policy, Insurance, Finances, and Other Service Coverage	
Code Name	Code Description and Questions
Applying for insurance or other services	Respondents' experiences applying for insurance and other services for x
Caregiver being paid for work	Does the respondent receive compensation for caring for x?
Caregiving as unpaid labor	Discussion of the caregiving of x as unpaid labor
Confusion about insurance	Did the respondent experience confusion regarding insurance including coverage, eligibility, application process, etc.?
COVID-19 and state policy	Discussion of policies within the context of COVID-19
Financial burden	Discussion of the financial burden of caring for x
Help with applying for insurance or other services	Did respondent or x receive help applying for insurance or other services?
Insurance challenges	Discussion of challenges with insurance
Insurance successes	Discussion of successes with insurance
Other financial contributions	Financial help received from entities outside of insurance and other formal services such as cash assistance from family, charity from church, GoFundMe, etc.
Other service coverage (ex. "Covered by the state")	Did the respondent discuss other types of care coverage such as services "covered by the state," community or charity services, etc.?
Services paid of out of pocket	Discussion of services paid out of pocket
Topic 3: Caregiving Experiences	
Code Name	Code Description and Questions
Advice for other caregivers	Respondents' advice for other caregivers
Caregiver challenges	Challenges experienced by respondent while caring for x

Caregiving successes	Successes experienced by respondent while caring for x
COVID-19 and caregiver experiences	Respondents' experiences with COVID-19
Desired services	Services that are desired by the respondent that x is not receiving
family and social network help with care	The respondent's experiences with family and other social network help with the care of x
Future care considerations	Respondents' discussion of possible future care changes
Home modifications and safety	Home modifications that the respondent has made while caring for x
No outside help with care	Respondents' experiences of receiving no outside help with the care of x
Personal and emotional burdens and caregiver stress	Respondents' experiences with personal and emotional burdens related to caregiving and overall caregiver stress
Service gaps or waitlists	Respondents' experiences with having to wait for services or experiences gaps in services for x
Tasks performed (typical day question)	The general tasks the respondent performs while caring for x
Useful services	Respondents' experiences with useful services for x
Topic 4: Experiences with Formal Care	
Code Name	Code Description and Questions
Adult day care experiences	Respondents' discussion of experiences with adult day care services
Challenges with services received	Respondents' discussion of the challenges experienced with the formal services received
COVID-19 and formal care	Discussion of formal care within the context of COVID-19
Home care experiences	Respondents' discussion of home care experiences
Medical professional experiences	Respondents' discussion of experiences with medical professionals
Nursing home experiences	Respondents' discussion of nursing home experiences
Social worker or case manager experiences	Respondents' discussion of experiences with social workers or case managers

Successes with services received	Respondents' discussion of the successes experienced with the formal services received
Support group experiences	Respondents' discussion of experiences with caregiver support groups
Topic 5: Background	
Code Name	Code Description and Questions
Demographics	Discussion of respondent and x's age, gender, race, and income
Duration of caregiving	How long has the respondent been a caregiver to x?
Level of care needed	How much care does x need (ex. driving to apts., bathroom care, medication management, etc.)?
Relationship between caregiver and x	Discussion of the relationship between caregiver and x
Residency change	Has the respondent or x changed residency since x has needed care?