

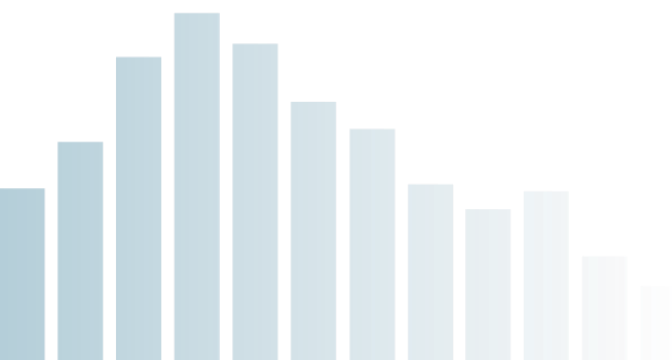


# Commonwealth Medicine

Public and Private Health Solutions

## Grandparents or Relative Caregivers Raising Children in Massachusetts Due to Parental Opioid Use

### Report of Study Results



September 2019

# Table Of Contents

- Background 3
- Massachusetts Data from National Survey 6
- Massachusetts Survey of Grandparents and Relative Caregivers Raising Children with No Birth Parent Present 12
- Key Informant Interviews 37
- Focus Groups 45
- Appendix 58

# Background



# MA Legislation Supporting Grandparents

On July 8, 2008, An Act Protecting Children in the Care of the Commonwealth was signed and included the establishment of the Commission on the Status of Grandparents Raising Grandchildren (Section 1 of Chapter 176, the Acts of 2008; codified as M.G.L. Chapter 3, section 69).



# Legislative Language: FY2019 MA State Budget

This report fulfills a request from the Massachusetts Legislature, articulated in the Budget Act for State Fiscal Year 2019:

*4590-2010..... For the department of elder affairs, which shall contract with the University of Massachusetts medical school to conduct a study on opioid use in the commonwealth specifically related to the impact opioid use has had and may continue to have on grandparents and other relatives raising related children; provided, that the study shall investigate and report on, among other topics: (i) the number of individuals in the commonwealth raising children of relatives; (ii) the number of individuals in the commonwealth raising grandchildren because 1 or both parents are addicted to an opioid drug; (iii) resources available to provide services to both the grandparent or other relative and to the children; and (iv) whether such services are coordinated in a manner that is beneficial to the grandparents and other relatives..... \$50,000*

This project started with available national data and a process to gather information directly from grandparents and stakeholders through key informant interviews and focus groups. Due to the lack of data on *ii* above (the number of individuals in the commonwealth raising grandchildren because 1 or both parents are addicted to an opioid drug), subsequent additional funding was sought to conduct a survey on this topic. Funding (\$17,500 each) was provided by the Office of the Child Advocate and the Attorney General's Office to conduct this survey.

Therefore, this report presents analysis and results from the following:

- Massachusetts data from the American Community Survey (ACS)
- A Massachusetts survey of grandparents and relative caregivers raising children with no birth parent present
- Key informant interviews
- Focus groups with grandparents

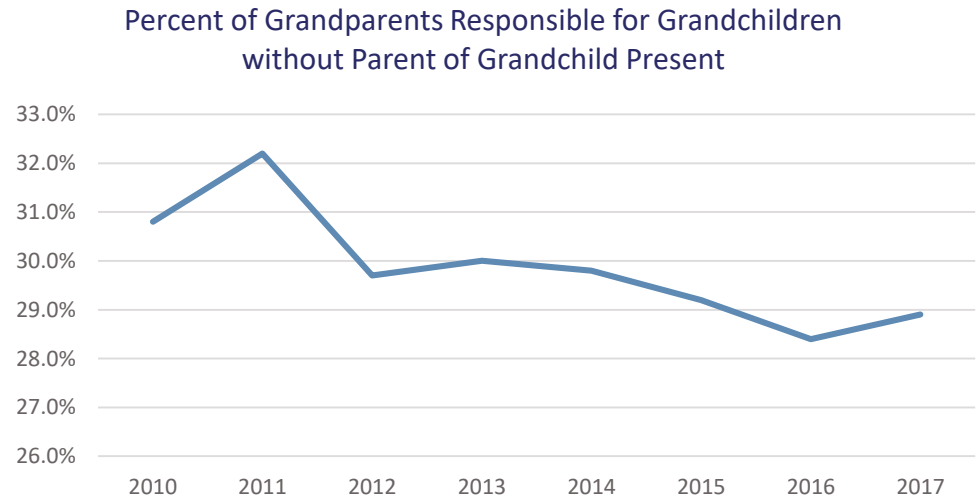
# Massachusetts Data from National Survey



# MA Grandparents Responsible for Grandchildren

- In Massachusetts, more than 30,000 grandparents are responsible for their grandchildren, either with or without the presence of a parent.
- Nearly one-third of these grandparents are responsible for grandchildren with no parent of grandchildren present.

Year	Number
2010	31,663
2011	33,041
2012	33,834
2013	34,228
2014	34,877
2015	35,407
2016	34,411
2017	33,468



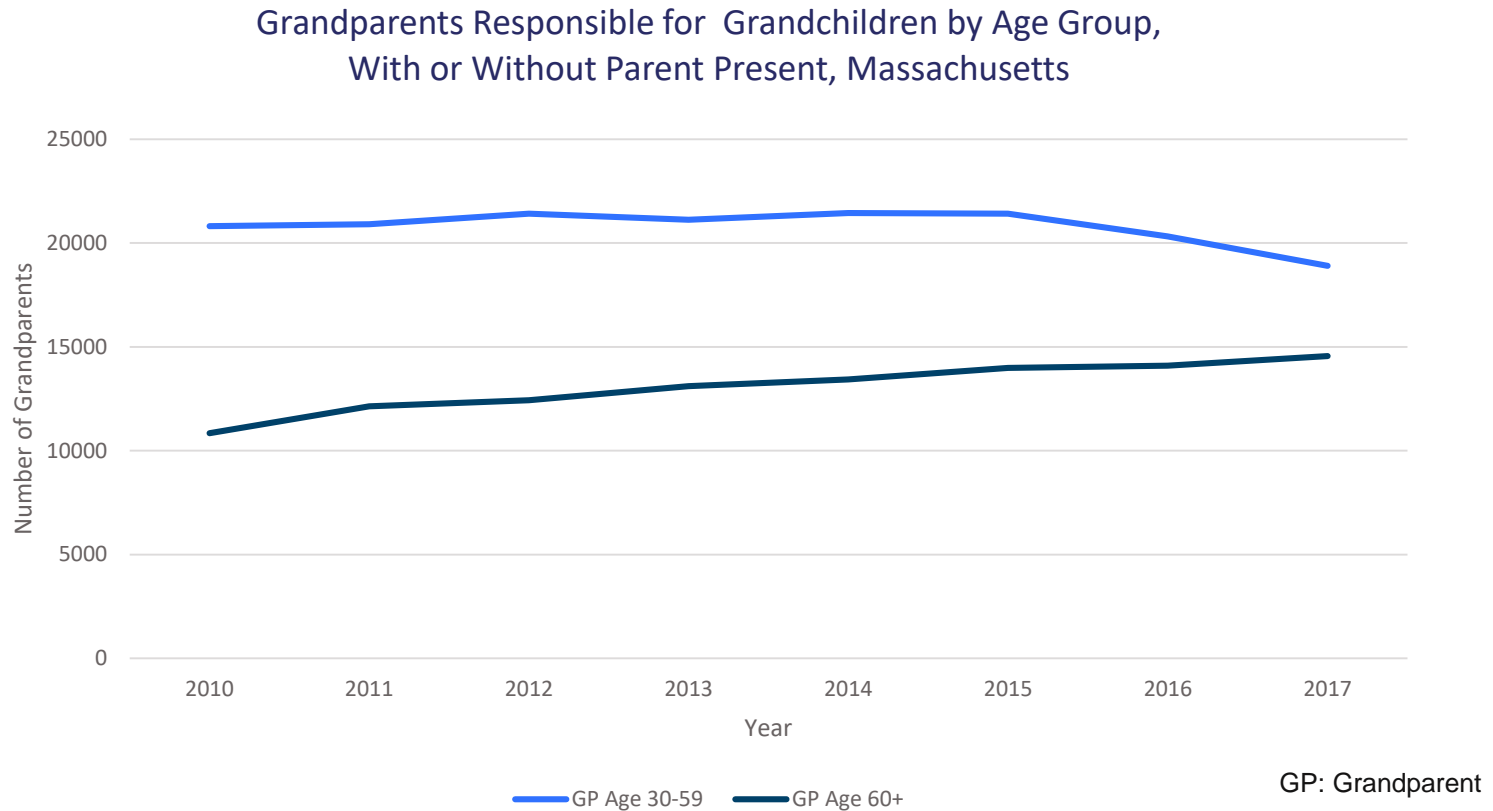
Data Source: 2010-2017 data of the American Community Survey (ACS) from American FactFinder, TableID: S1002, last accessed August 2019, U.S. Census Bureau

Note: The findings are based on answers of “Yes” to both of the following ACS questions:

25a “Does this person have any of his/her own grandchildren under the age of 18 living in this house or apartment?”

Household membership constructed through Census Bureau analysis based on various other survey questions to determine if the parents are living in the household; the responsibility question is 25b “Is this grandparent currently responsible for most of the basic needs of any grandchildren under the age of 18 who live in this house or apartment?”

# MA Grandparents Responsible for Grandchildren by Age Group, With or Without Parent Present



Data Source: 2010-2017 ACS data from American FactFinder, TableID: S1002, U.S. Census Bureau, last accessed August 2019

Note: The findings are based on the following ACS questions:

4 "What is person[X]'s age and date of birth?"

Answers of "Yes" to both:

25a "Does this person have any of his/her own grandchildren under the age of 18 living in this house or apartment?"

25b "Is this grandparent currently responsible for most of the basic needs of any grandchildren under the age of 18 who live in this house or apartment?"



# Socio-Demographic Characteristics of MA Grandparents Responsible for Grandchildren, With or Without Parent Present

N = 33,468

## Gender

- 66% grandmothers

## Disability\*

- 24% have a disability

## Marital Status ("Now Married")

- 66% are married

## Race

- 72% White
- 13% Black
- 5% Asian
- 10% Other

## Median family income

- Parent present: \$68,965
- No parent present: \$37,220

Data Source: 2017 ACS from American FactFinder, U.S. Census Bureau, last accessed August 2019

Note: The findings are based on the following ACS questions:

Answers of "Yes" to both 25a and 25b:

25a "Does this person have any of his/her own grandchildren under the age of 18 living in this house or apartment?"

25b "Is this grandparent currently responsible for most of the basic needs of any grandchildren under the age of 18 who live in this house or apartment?"

3 "What is person[X]'s sex?"

6 "What is person[X]'s race?"

20 "What is this person's marital status?"

47 "What was this person's total income in the past 12 months."

\* "Disability" is based on a "Yes" response to any of the following questions:

17a "Is this person deaf and/or does s/he have difficulty hearing?"

17b "Is this person blind or does s/he have serious difficulty seeing even when wearing glasses?"

18a "Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?"

18b "Does this person have serious difficulty walking or climbing stairs?"

18c "Does this person have difficulty dressing or bathing?"

19 "Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?"

# Length of Time that MA Grandparents Have Been Responsible For Grandchildren, With or Without Parent Present

Year									
2015			2016			2017			
Grandparents (Total and by Age Group)									
Length of Time	All GPs (N=33,992)	30-59 years (N=20,232)	60+ years (N=13,760)	All GPs (N=30,582)	30-59 years (N=16,949)	60+ years (N=13,633)	All GPs (N=32,808)	30-59 years (N=16,920)	60+ years (N=15,888)
Less than 6 months	9%	7%	11%	5%	7%	2%	9%	9%	9%
6 to 11 months	7%	7%	7%	13%	19%	6%	7%	5%	10%
1 to 2 years	24%	30%	16%	21%	28%	11%	22%	28%	15%
3 to 4 years	18%	19%	18%	16%	16%	15%	20%	24%	17%
5 or more years	41%	37%	48%	46%	30%	66%	42%	34%	49%

GP: Grandparent

Data Source: UMMS Analysis of 2015-2017 ACS data

Note: The findings are based on the following ACS questions:

25b "Is this grandparent currently responsible for most of the basic needs of any grandchildren under the age of 18 who live in this house or apartment?"

25c "How long has this grandparent been responsible for these grandchildren? If the grandparent is financially responsible for more than one grandchild, answer the question for the grandchild for whom the grandparent has been responsible for the longest period of time."

Note: The population size estimates (N) vary somewhat from slide 7 as these results are based on an analysis of ACS data at the individual level vs. aggregate data from American Fact Finder.

# MA Grandparents Responsible for Grandchildren by Location and Age, With or Without Parent Present

- Middlesex, Worcester, and Essex counties (red circles) have the most grandparents who are responsible for grandchildren
- About 50% of grandparents responsible for grandchildren in Middlesex, Norfolk, and Worcester counties (green boxes) are older than 60



Data Source: 2017 ACS from American FactFinder, U.S. Census Bureau, last accessed December 2018

Note: The findings are based on the following ACS questions:

25b "Is this grandparent currently responsible for most of the basic needs of any grandchildren under the age of 18 who live in this house or apartment?"

4 "What is person[X]'s age and person[X]'s date of birth?" as well as contact information of survey respondents

# Massachusetts Survey of Grandparents and Relative Caregivers Raising Children with No Birth Parent Present



# Survey Methodology

## Who?

A total of 415 grandparents and other relatives raising children in Massachusetts without the presence of either birth parent completed the survey. An additional 62 respondents were screened out of the survey because they did not meet one or more of the criteria of being a relative caregiver, no birth parent living with the child, and being a Massachusetts resident.

## When?

March 27 to May 21, 2019

## How?

The survey was designed by the Office of Survey Research (OSR) at Commonwealth Medicine, UMass Medical School, with input from the the Commission on the Status of Grandparents Raising Grandchildren and other stakeholders. OSR programmed the survey for online administration and the link to the survey was disseminated by the Commission through its Constant Contact email distribution list as well as through other channels, such as support group meetings and Family Resource Centers.

## Limitations

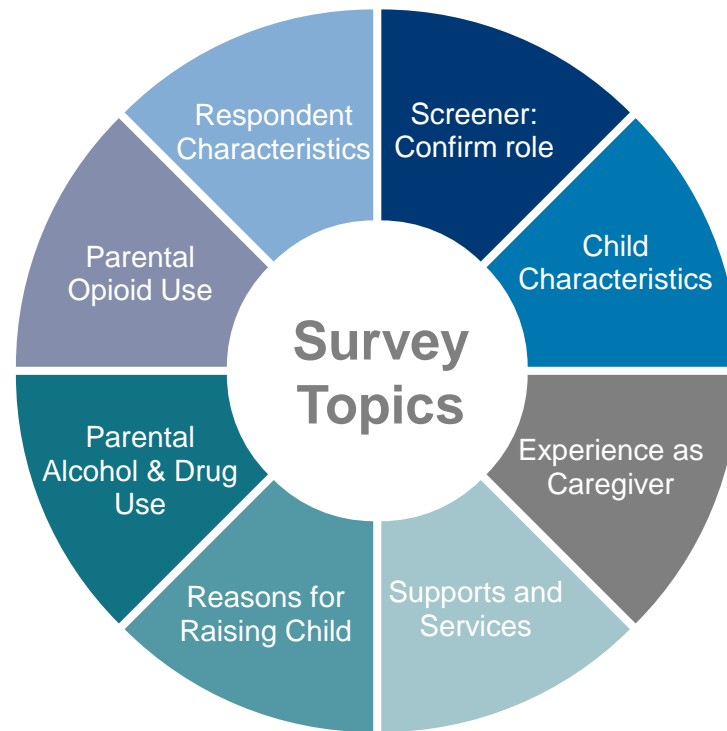
The population of grandparents and relative caregivers in the state who are raising children without the presence of either birth parent is unknown, and therefore the survey relied upon a convenience sampling approach as described above, as opposed to a representative sample of the population.

The total number of completed surveys (n=415) did not yield sufficient sample sizes to analyze the results by subgroups, such as age, length of time raising children, parental opioid use, etc.

# Survey Content

The survey was designed to capture information across a variety of topic areas that were of most interest to the Commission on the Status of Grandparents Raising Grandchildren and other stakeholders

- Respondents were screened at the start of the survey to confirm that they were a relative caregiver for a child under the age of 18, that no birth parent was living with the child, and that they were a resident of Massachusetts



*See Appendix for the full content of the online survey instrument.*

# Respondent Caregiver Profile



# Respondent Caregiver Background

## Respondent Caregiver Demographics

<b>Age</b>	25 to 44	3%
	45 to 54	22%
	55 to 64	45%
	65 or older	30%
<b>Gender</b>	Female	91%
<b>Marital Status</b>	Single, never married	6%
	Married/Living with partner	56%
	Divorced/Separated/Widowed	38%
<b>Race/ Ethnicity</b>	White, non-Hispanic	83%
	Hispanic or Latino	4%
	Black or African-American	7%
	Multi-race or other race	6%

<b>Education</b>	High school or less	22%
	Some college or 4-year degree	60%
	More than 4-year degree	18%
<b>Employment</b>	Currently employed	57%
<b>MA Region</b>	Boston/Metro Boston	19%
	Central	15%
	Northeast	16%
	Southeast	34%
	West	17%

Q38 What is your age? (n=413)  
 Q39 Are you male or female? (n=413)  
 Q40 What is your marital status? (n=410)  
 Q41/42 Race/Ethnicity (n=409)

Q43 What is the highest grade or level of school that you have completed? (n=410)  
 Q44/Q45 Currently working at a job for pay (n=411)  
 Q46 Which region of the state do you live in? (n=411)



# Respondent Caregiver Health

## Respondent Caregiver Health Status

<b>Physical Health</b>	Excellent	11%
	Very good	36%
	Good	38%
	Fair/Poor	15%
<b>Mental or Emotional Health</b>	Excellent	12%
	Very good	32%
	Good	39%
	Fair/Poor	17%
<b>Physical Disability</b>		19%

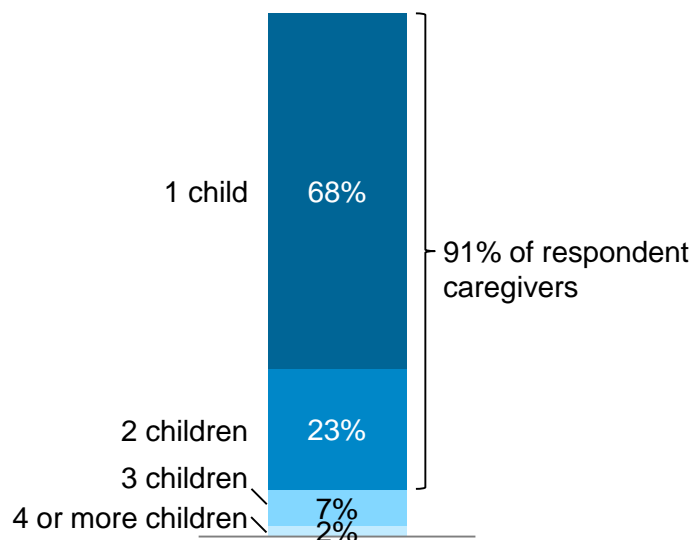
Q35 In general, how would you rate your physical health? (n=414)

Q36 In general, how would you rate your mental or emotional health? (n=413)

Q37 Do you have a physical disability that makes it difficult to walk, move or get around? (n=412)

# Respondent Caregiver Profile

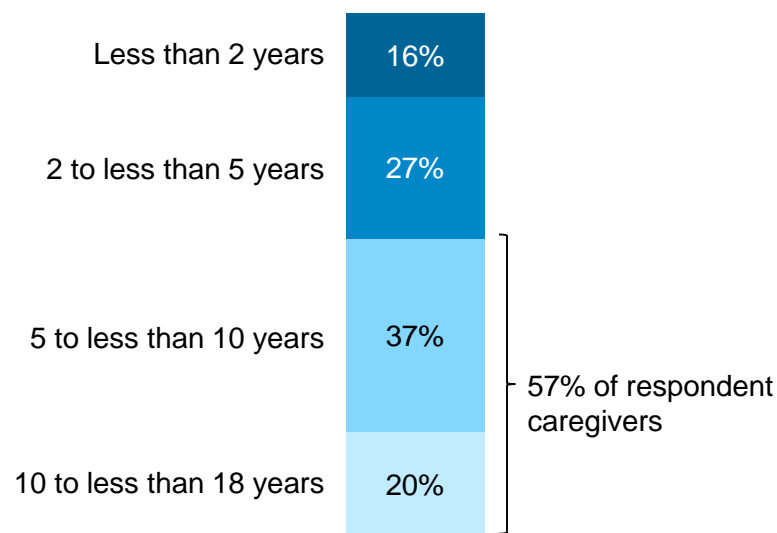
## Number of Children in Care



### Total Number of Children in Care

415 grandparents/other relative caregivers report caring for 601 children

## Length of Time as Caregiver\*



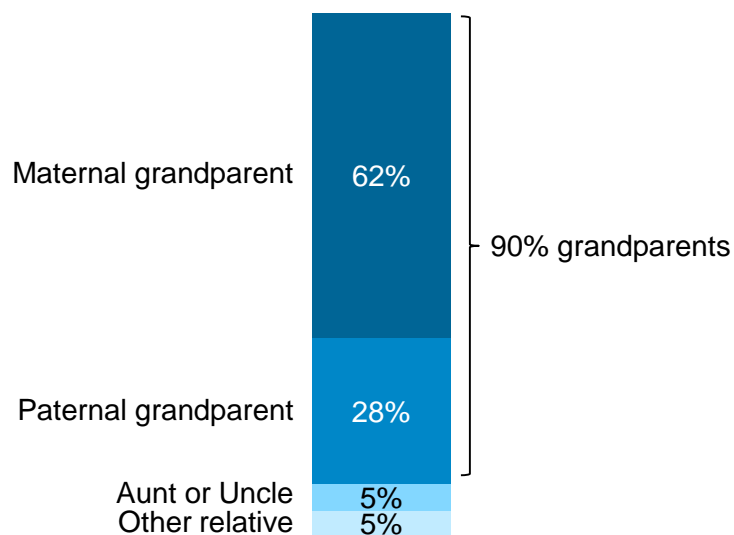
\* If a caregiver is caring for more than one child, the length of time as caregiver for the oldest child is displayed here.

Q4 For how many children under age 18 are you the primary caregiver, with no birth parent present? (n=415)

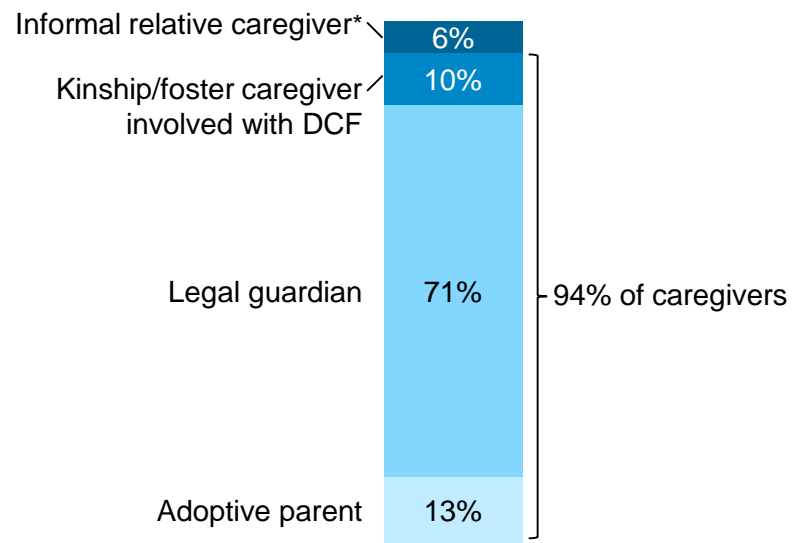
Q6 How long have you been the primary caregiver for this child? (n=415)

# Respondent Caregiver Profile (Cont.)

## Family Relationship to Child



## Legal Relationship to Child



\* Informal relative caregivers are specified as not involved with any court, DCF, or other authorities. Of them, most (21 out of 26 respondents) report having a signed affidavit or other document from child's birth parent that allows them to make decisions on the child's behalf.

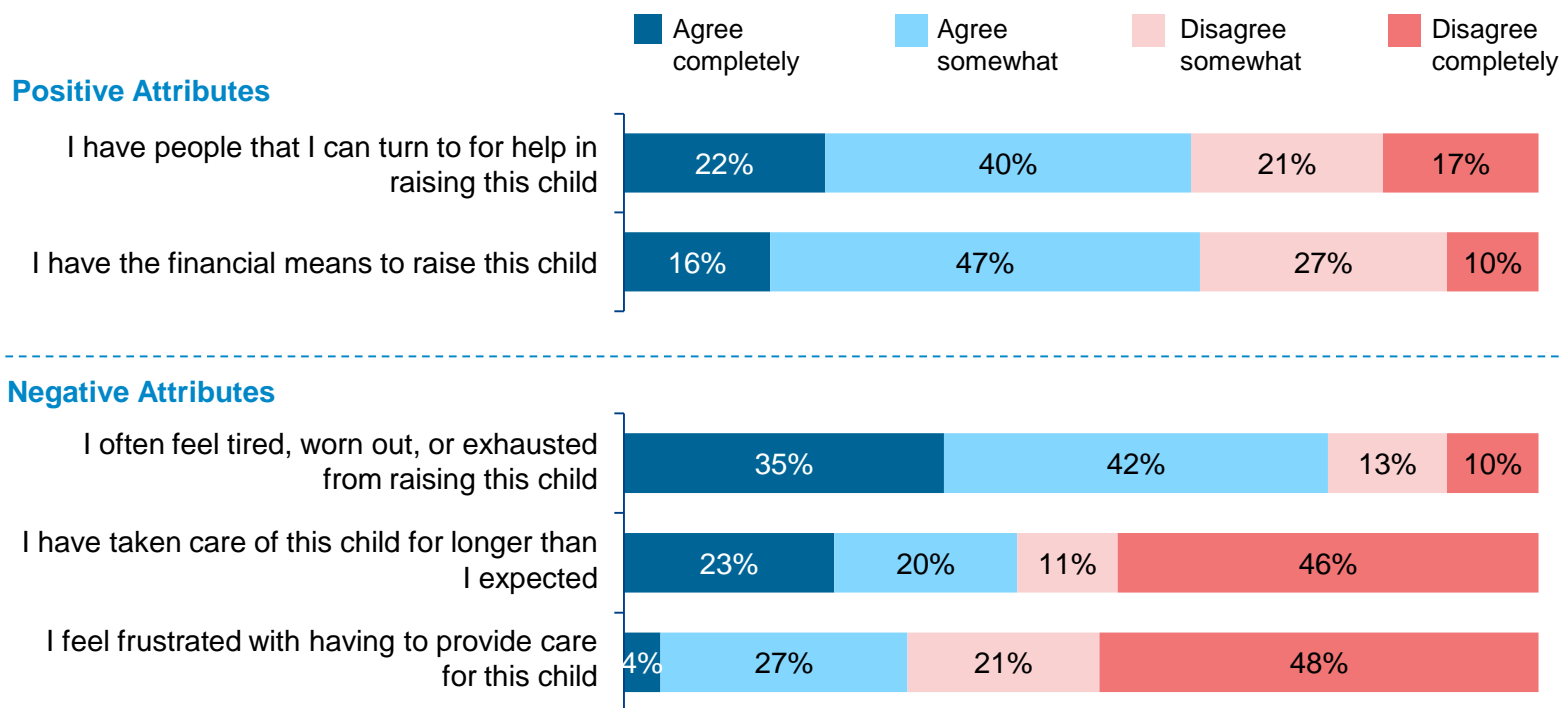
Q10 How are you related to this child? (n=414)

Q15 Which of the following best describes the type of caregiver you are to this child? (n=414)

Q16 Do you have a signed affidavit or other document from this child's birth parent that allows you to make important decisions on this child's behalf? (n=26)

# Experience as Caregiver

## Respondent Caregiver Ratings on Perceptual Attributes Related to their Experience



Q26 To what extent do you agree or disagree with each of the following statements? Please select a response for each item. (Variable base per item; n=404 to 414)

# Child Profile



# Child Demographics

## Characteristics of Child in Respondents' Care

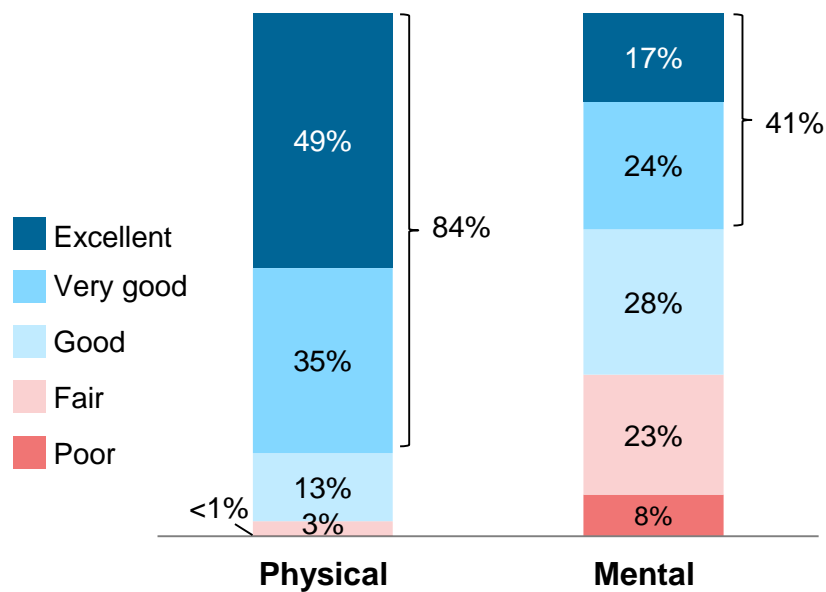
<b>Age</b>	Less than 2 years	3%
	2 to less than 5 years	13%
	5 to less than 10 years	39%
	10 to less than 15 years	35%
	15 to less than 18 years	10%
<b>Gender</b>	Female	47%
<b>Race/Ethnicity</b>	White, non-Hispanic	67%
	Hispanic or Latino	10%
	Black or African-American	9%
	Other	14%

Q5 What is this child's age? (n=589)

Q7 Is this child male or female? (n=589)

Q8/9 Race/Ethnicity (n=586)

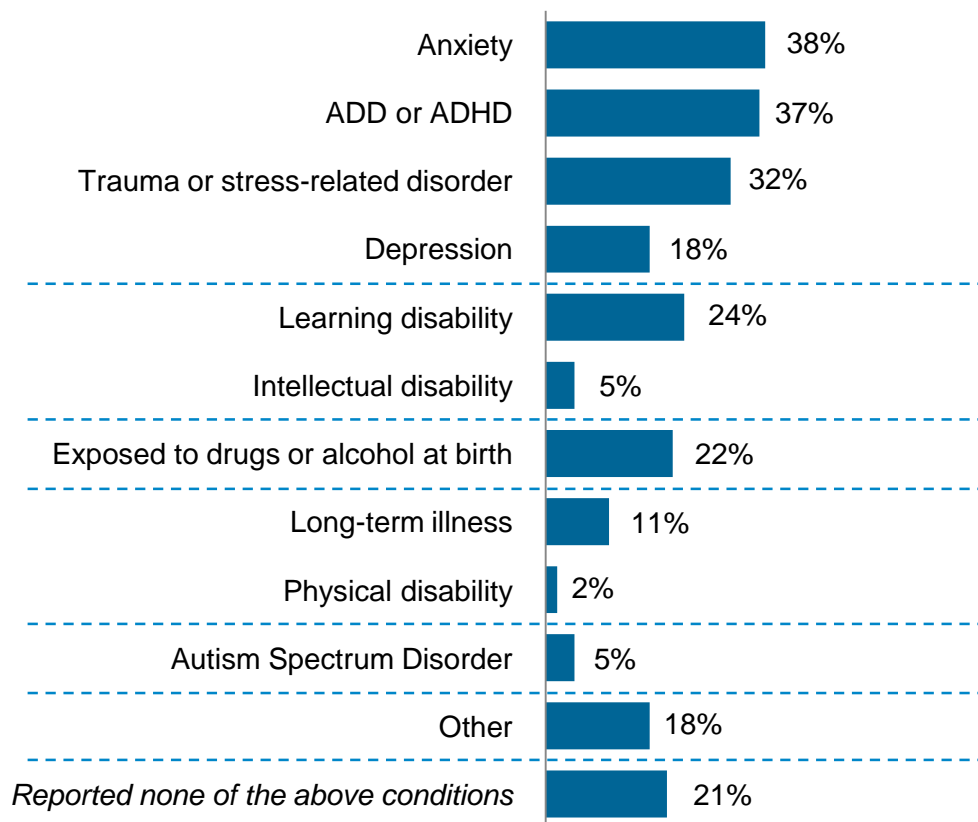
## Respondent Caregivers' Ratings of Child's Physical and Mental Health



Q11 In general, how would you rate this child's physical health? (n=415)  
Q12 In general, how would you rate this child's mental or emotional health? (n=414)

# Child's Health (Cont.)

## Respondent Caregivers' Report of Conditions Experienced by Child



Q13 Has a doctor, other health care provider, or educator ever told you that this child has any of the following? Please select all that apply. (n=415)

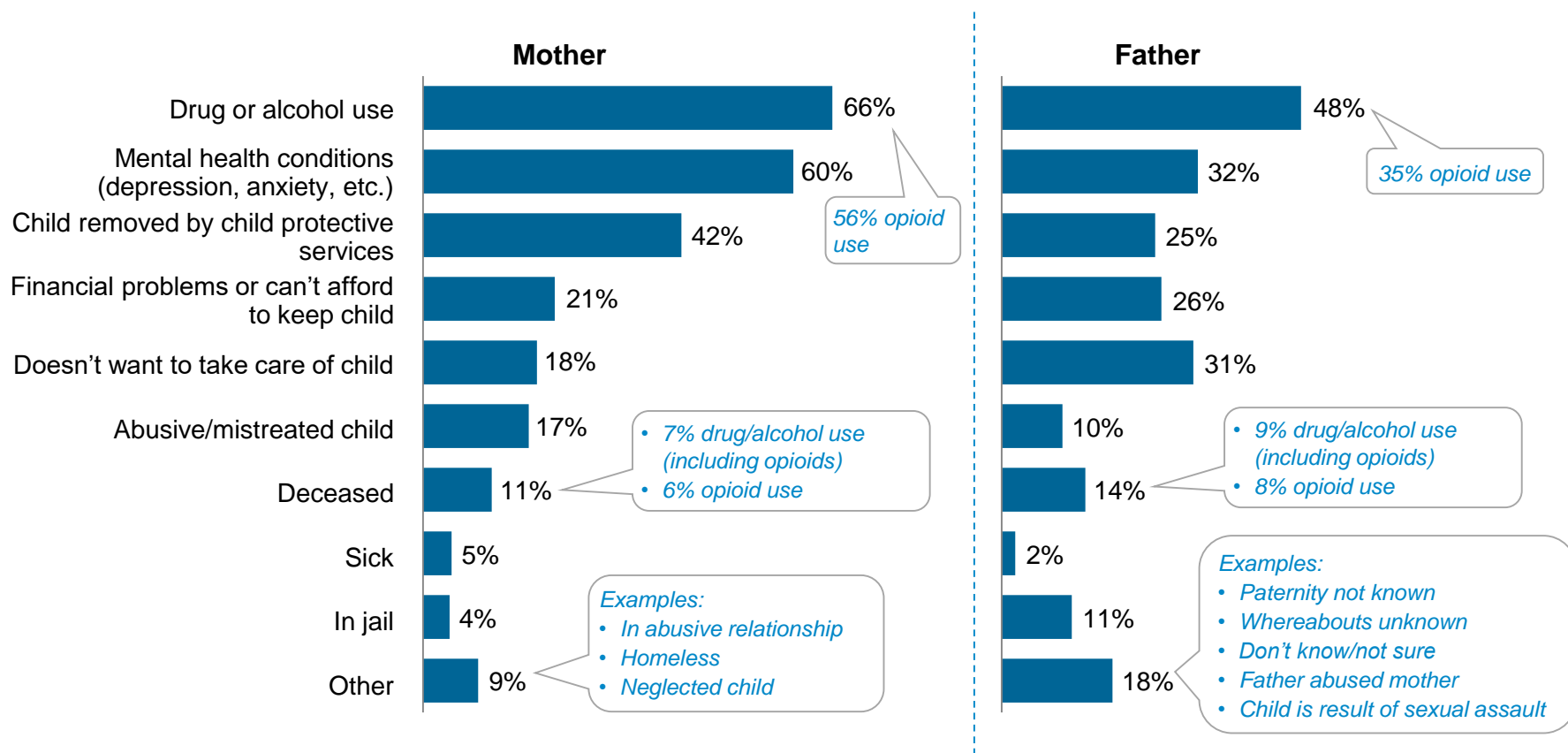


# Parental Opioid Use and Other Reasons for Grandparent or Other Relative Raising Child



# Reasons Child is Not with a Birth Parent

## Respondent Caregivers' Report of Reasons Why Child is Not Living with Mother or Father



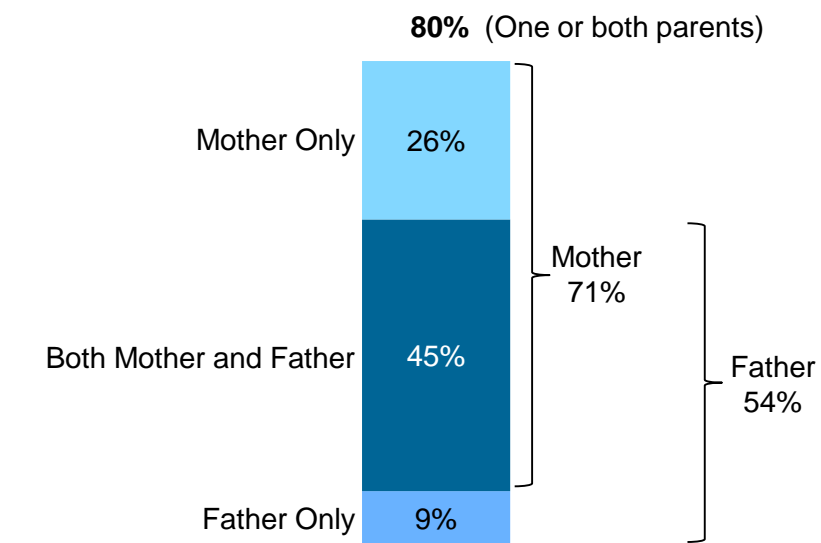
Reasons selected by <3% of caregivers are not shown

Q27 Why is this child not living with his or her birth mother? Please select all that apply. (n=414)  
 Q31 Why is this child not living with his or her birth father? Please select all that apply. (n=407)

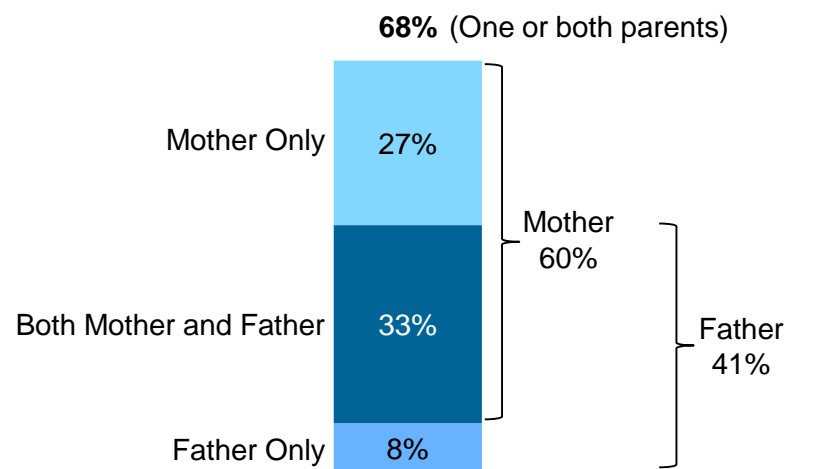
Q30 Please select the cause of this child's mother's death. (n=46)  
 Q34 Please select the cause of this child's father's death. (n=55)

# Reason Respondent is Raising Child: Parental Drug/Alcohol/Opioid Use

## Reason: Drug or Alcohol Use\* (including Opioids)



## Reason: Opioid Use\*



\* Estimates include drug or alcohol use cited as a reason why child is not with birth parent, as well as when "deceased" is selected as a reason and the cause of death is cited as drug or alcohol use.

Note: Estimates of maternal drug/alcohol/opioid use are higher than paternal most likely due to the nature of the survey population – the majority of survey respondents are maternal grandparents, who are likely to have a better understanding of the mother's situation than of the father's.

Q27/31/30/34 Why is this child not living with his or her birth mother/birth father? [Drug or alcohol problems or Deceased – drug/alcohol as reason].(n=415)

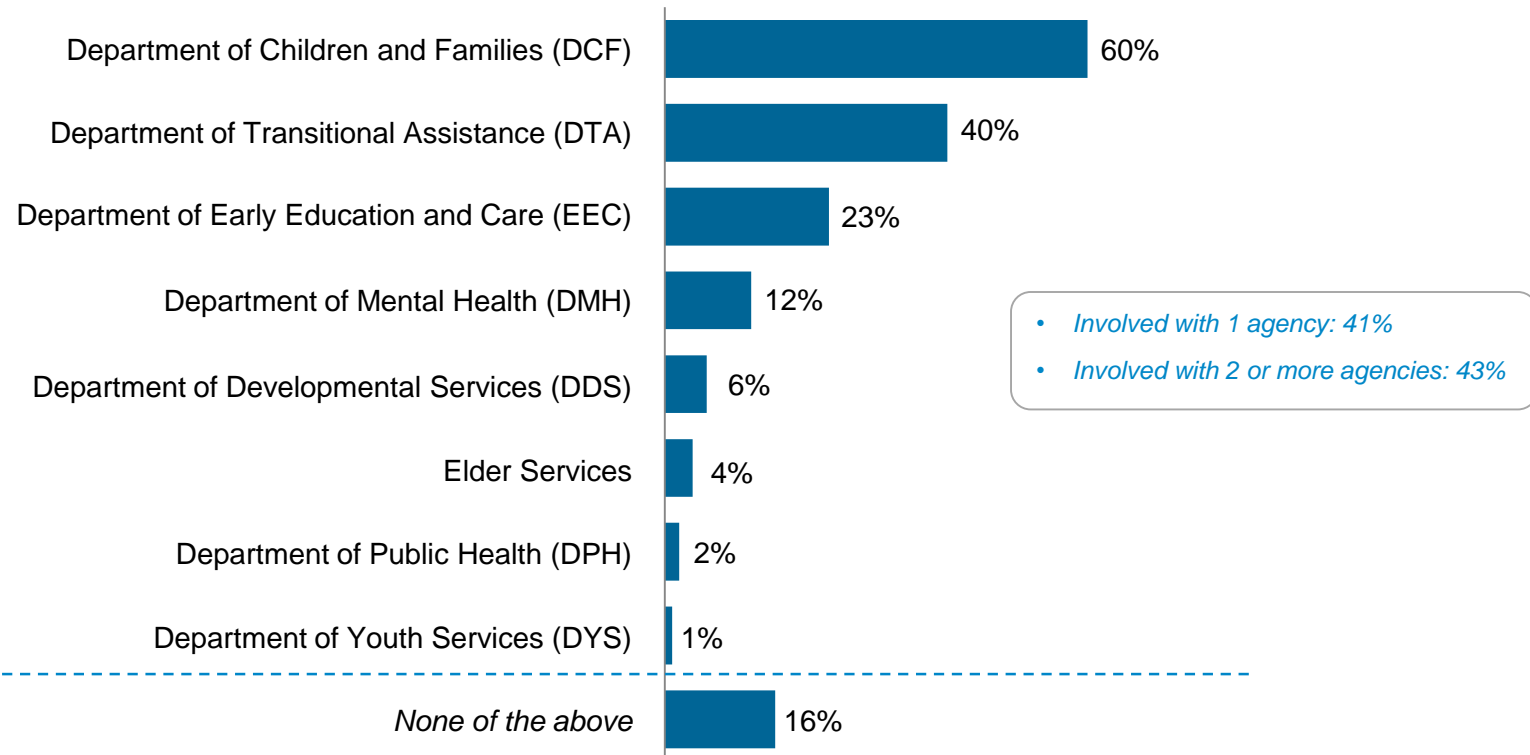
Q29/33/30/34 To the best of your knowledge, has this child's mother/father had problems with any of the following drugs or substances? [Heroin, prescription painkiller or opioid, such as oxycodone, fentanyl, morphine, etc.](n=415)

# Awareness and Use of Supports and Services



# Involvement with State-Funded Services

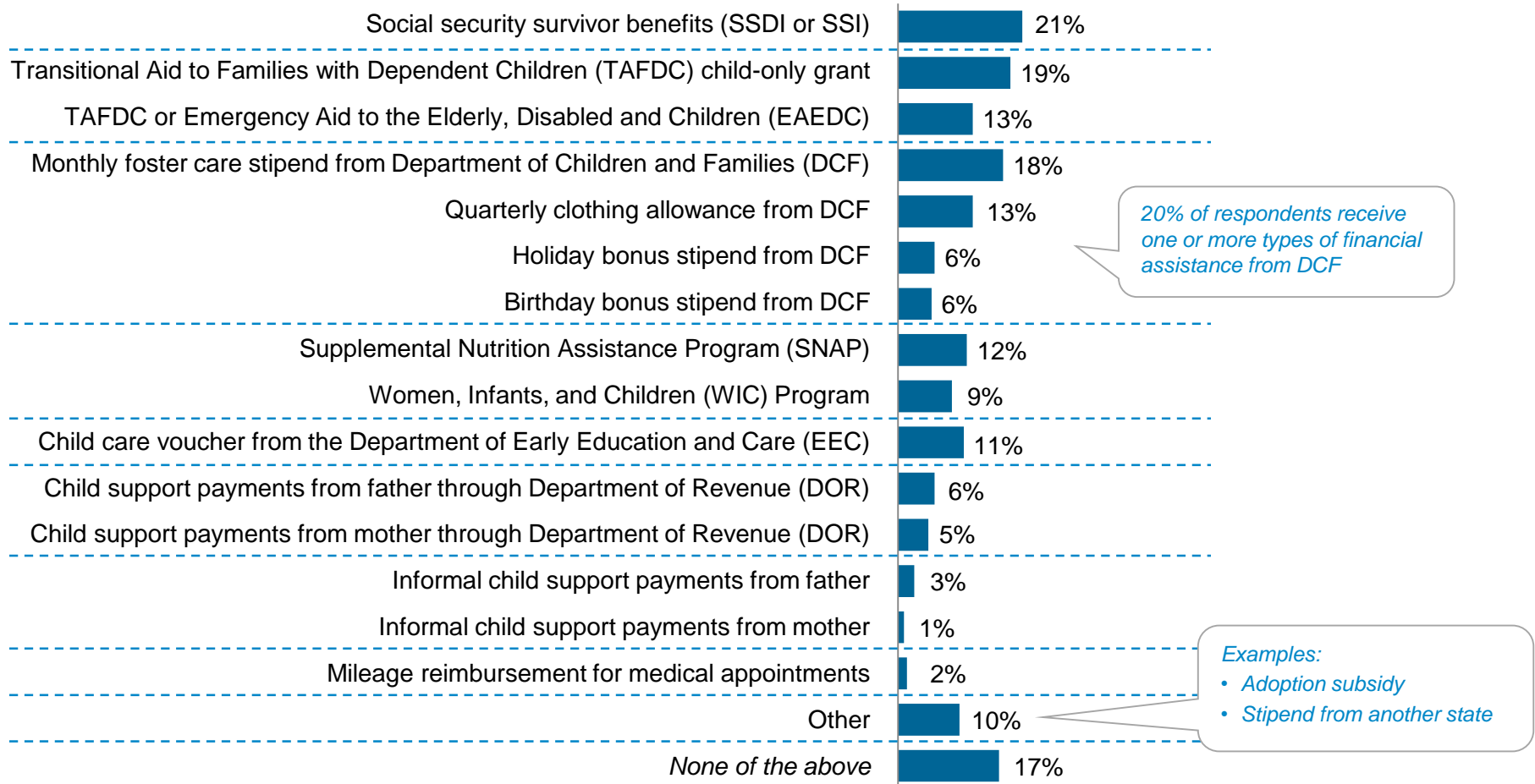
## Respondent Caregiver or Child Involvement with State-Funded Services



Q17 Have you or this child been involved with or received services from any of the following state agencies? Please select all that apply. (n=410)

# Sources of Financial Assistance

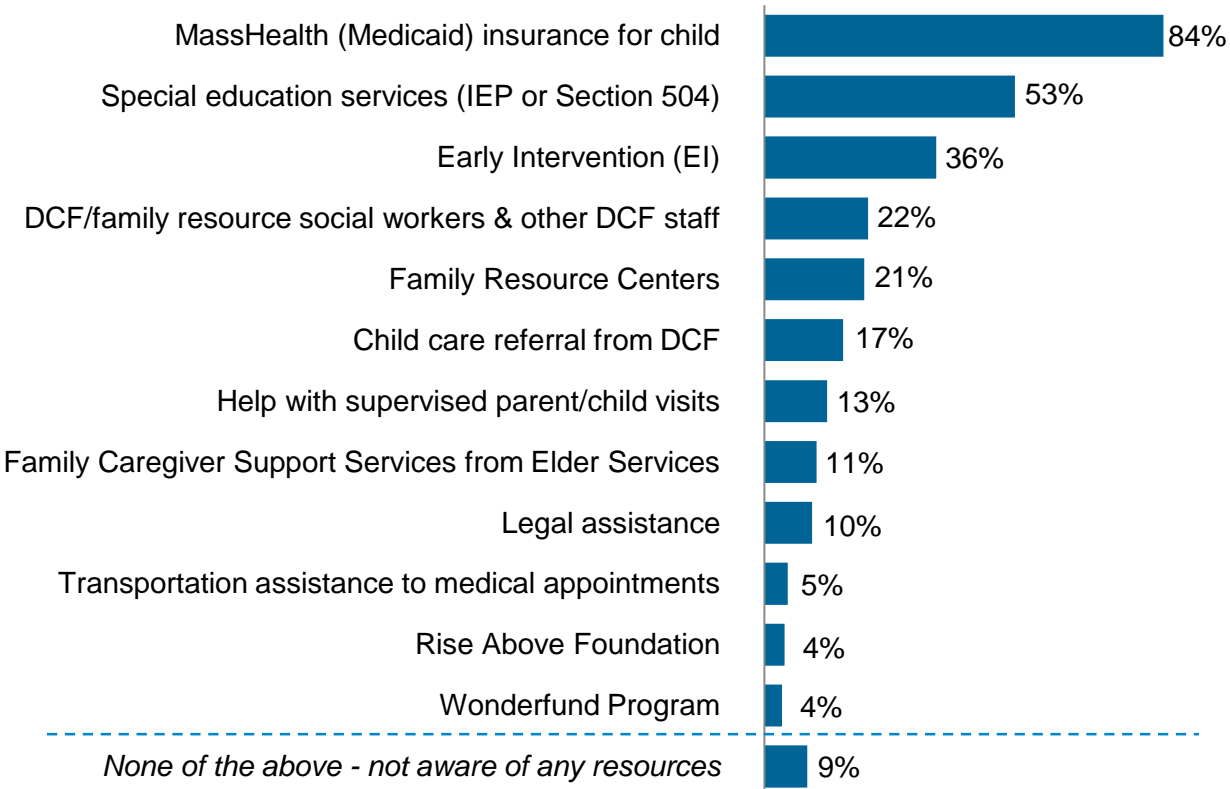
## Respondent Sources of Financial Assistance to Care for the Child



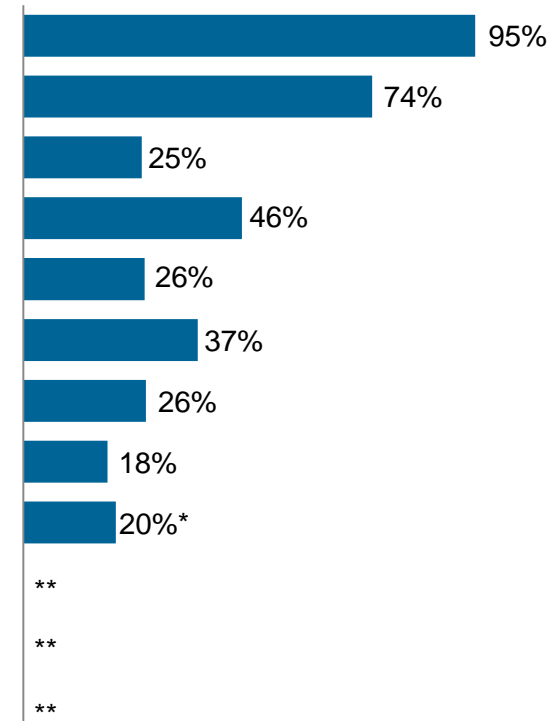
Q18 Do you receive financial assistance to care for this child from any of the following sources? Please select all that apply. (n=409)

# Service Awareness and Usage

## Respondent Caregivers' Awareness of Services



## Receive Services – Among Those Aware –



\* Low base size

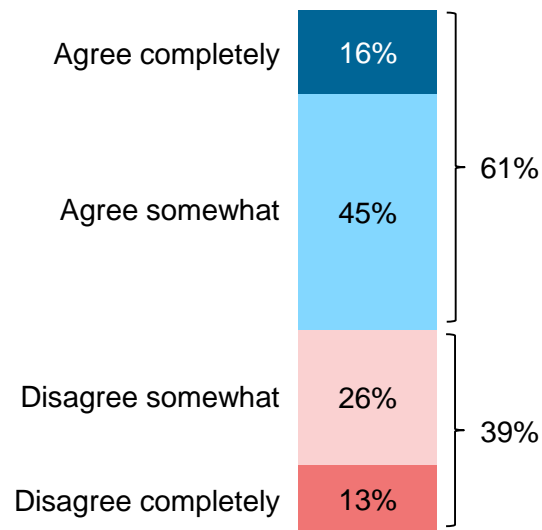
\*\* Not shown due to insufficient base size

Q19 Before taking this survey, were you aware that the following services may be available to assist grandparents and other relatives who are primary caregivers for a child with no birth parent present? *Please select all that apply.* (n=409)

Q20 Do you receive any of the following services to assist you in caring for this child? *Please select all that apply.* (n=353)

# Understanding of Available Services

***“I have a good understanding of the services available to help me raise this child”***

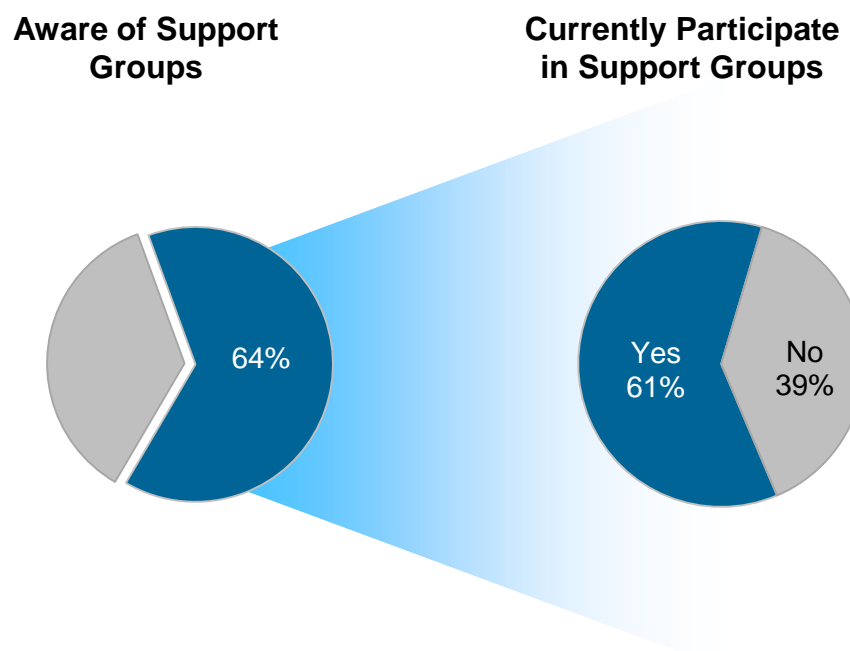


Q26 To what extent do you agree or disagree with each of the following statements? I have a good understanding of the services available to help me raise this child (n=410)



# Support Group Awareness and Participation

## Respondent Caregivers' Awareness of and Participation in Support Groups



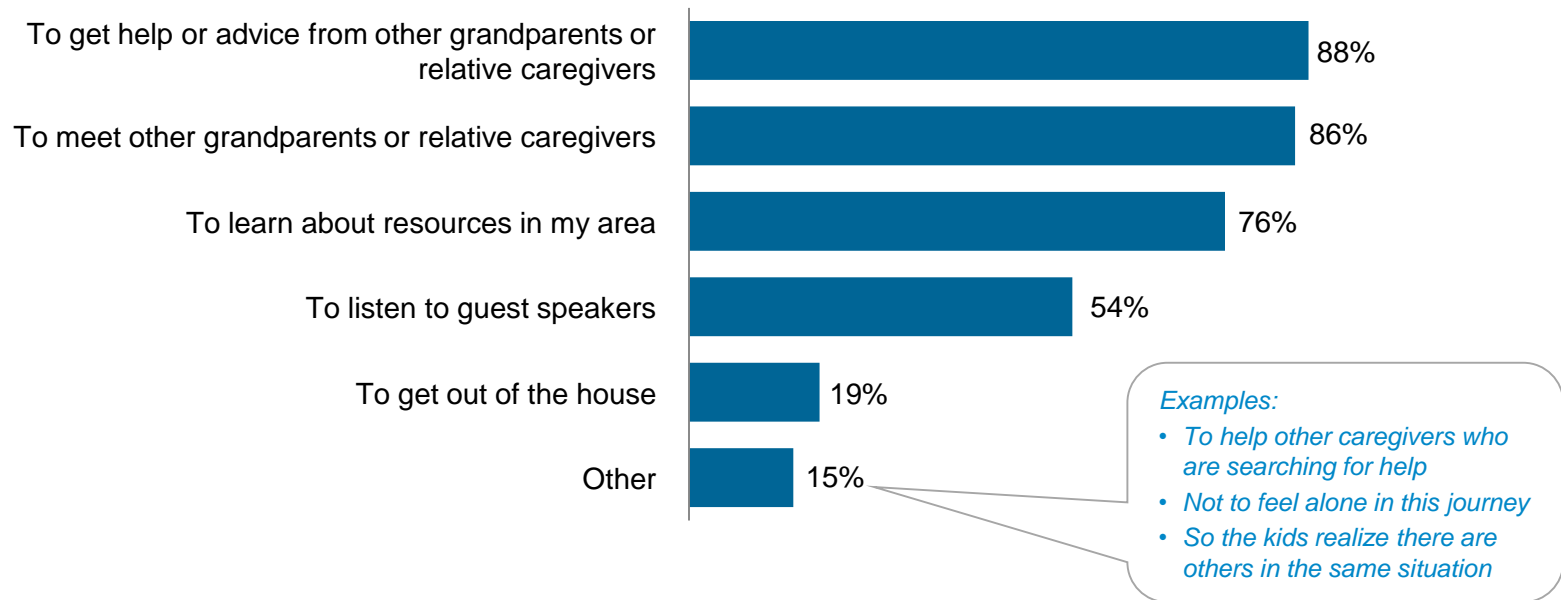
Q21 Are you aware of any support groups in your community for grandparents and other relatives who are primary caregivers for a child with no birth parent present? (n=414)

Q22 Do you currently participate in any support groups for grandparents and other relatives who are primary caregivers for a child with no birth parent present? (n=266)

# Motivators for Support Group Participation

## Respondent Caregivers' Reasons for Participating in Support Groups

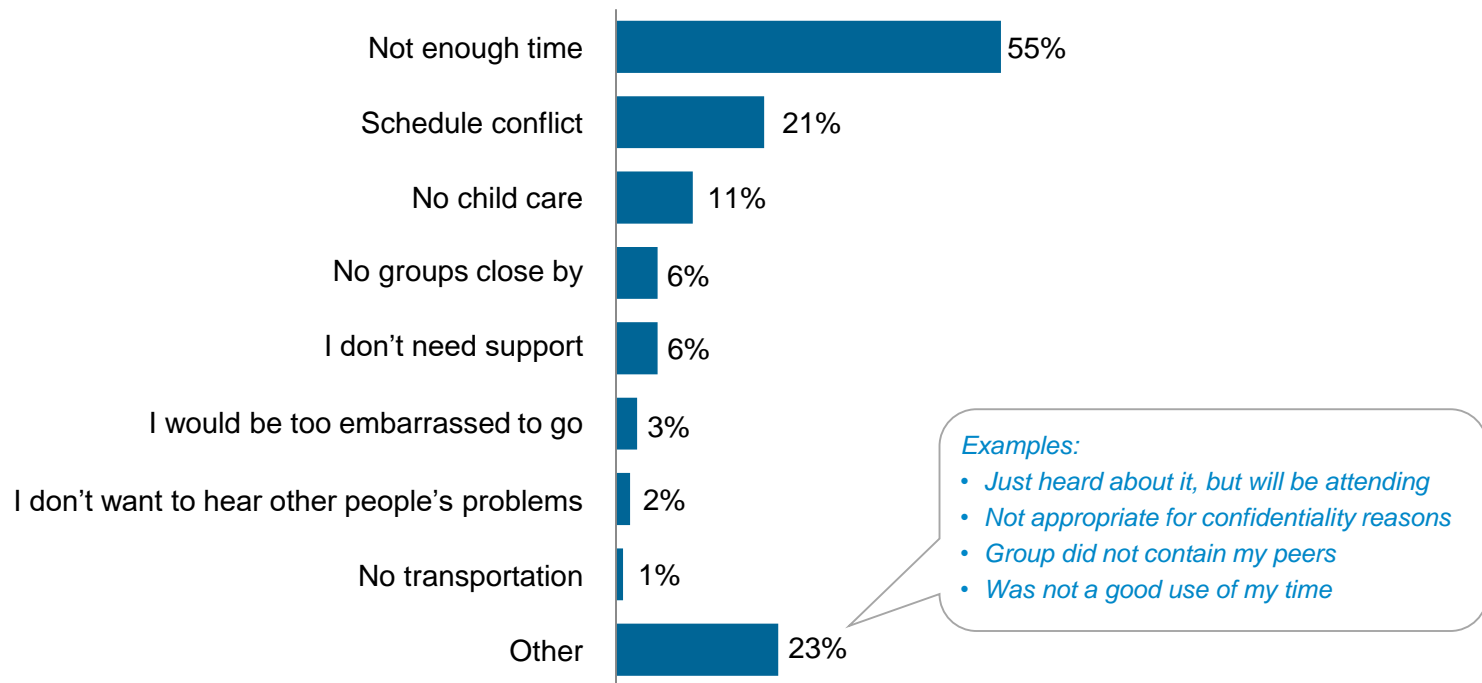
– Among Those Who Currently Participate –



Q23 Why did you decide to participate in a support group? Please select all that apply. (n=162)

# Barriers to Participation in Support Groups

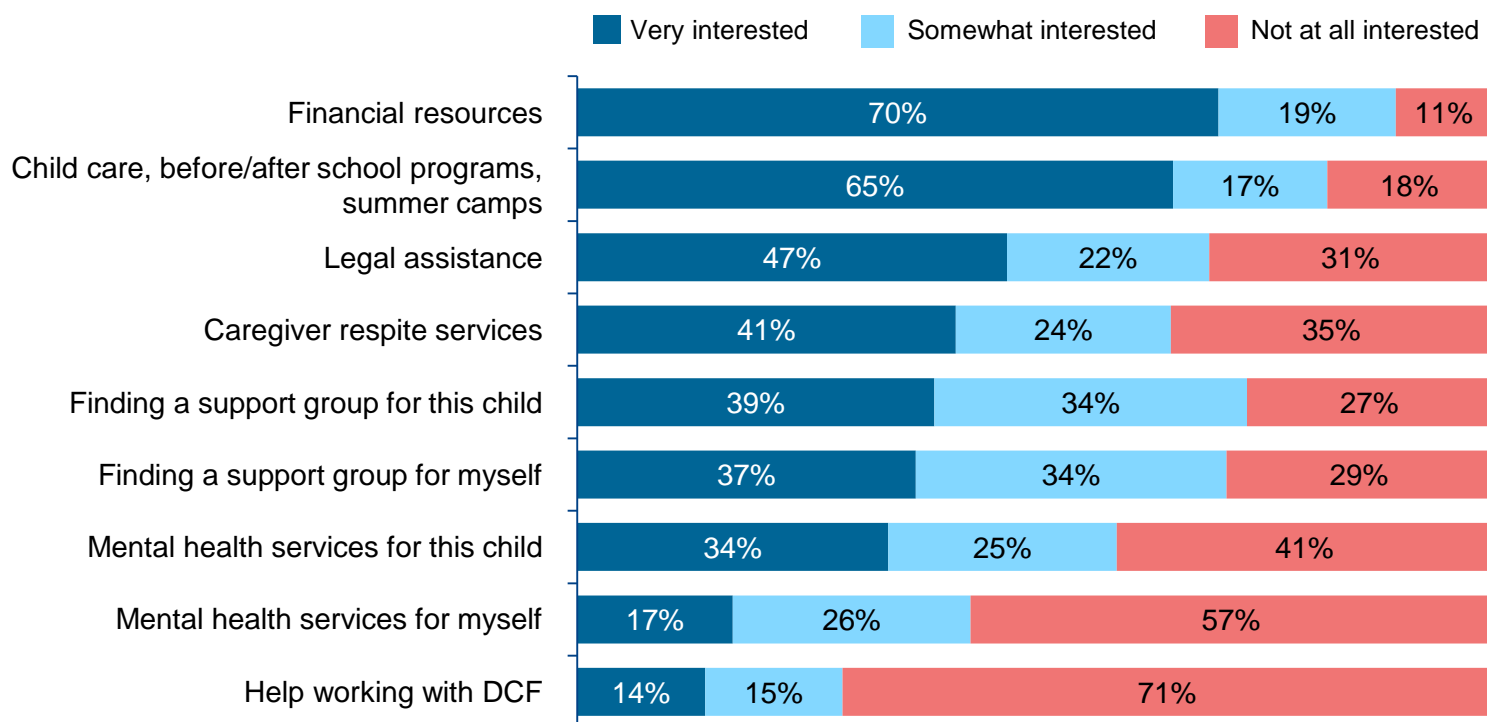
## Respondent Caregivers' Reasons for Not Participating in Support Groups – Among Those Who Do Not Currently Participate –



Q24 Why did you decide **not** to participate in a support group? Please select all that apply. (n=101)

# Interest in Potential Services and Supports

## Respondent Caregivers' Ratings of Interest in Potential Services



Q25 How interested are you in the following services to assist you in caring for this child? Please select a response for each item. (Variable base; n=312 to 382)

# Key Informant Interviews



# Key Informant Interviews - Subjects

**Six interviews up to 60 minutes, five with Massachusetts Public Employees and one with a national thought leader, between October 2018 and February 2019**

- Assistant Deputy Court Administrator of the Probate and Family Court
- Director of Office of the Child Advocate
- Director of the Grandparents Commission
- Public Sector Legal Services Lawyer
- Policy Analyst for Economic Assistance & Employment Programs, Department of Transitional Assistance
- Deputy Executive Director - Generations United (national)

# Key Informant Interviews – Key Topics

- Background and agency mission
- Activities related to grandparents raising grandchildren
- Grandparent experiences raising grandchildren
- Grandparent service needs
- State and national initiatives to address needs of grandparents raising grandchildren

*See Appendix for the semi-structured interview guide.*

# Key Informant Identified Strengths

- Strong outreaches to local communities by the Commission on the Status of Grandparents Raising Grandchildren
  - ✓ Annual grandparent conference, including workshops to empower grandparents
  - ✓ 40+ grandparent support groups across Massachusetts
  - ✓ Regular training of providers to support grandparents raising grandchildren
- Referral to service agencies by Family Resource Centers
- “Tip Sheet series” for families by the Generations United
- Other important resources:
  - Aging service such as the National Family Caregivers Support Program offers grandparents raising grandchildren financial resources and programs
  - Community-based and faith-based organizations offer a variety of additional supports



# Key Informant Identified Weaknesses

- Limited legal services are available to represent grandparents raising grandchildren
- Services vary across the state
- Eligibility criteria vary depending on service agency
- Probate and Family Court lack statutory responsibilities and funding for grandparents raising grandchildren
- Data are inadequate to reveal details for policy actions

*“...important to bring the other agencies up to date and make sure that everyone is sharing the same information to minimize the amount of mismatched information that is out there.”*

*“There could be better coordination to help cut down on misinformation and ensure that each agency understand the other agency’s work.”*

# Key Informant Feedback on Navigating The System Of Care

- Some grandparents raising grandchildren lack knowledge on how to navigate support systems
- Feedback was given by some indicating confusion about rights and benefits
- A portion of grandparents face legal barriers and lack legal representation as relative caregivers
- There is a perceived stigma/fear about working with state agencies among some grandparents



# Key Informant Feedback on Needs

## Information about available services

- Detailed information on how to get services and supports
- Support groups and caregiver resources focused on navigation of services across agencies
- Better understanding of legal process for custody and referrals

*“Policy and legislative advocacy...legal representation for grandparents in a custody dispute”*

## Training and education on services and eligibility rules

- For providers, including case managers and social workers within the courts, DCF, elderly services, and other service agencies
- For people who interact with grandparents raising grandchildren, including schools, healthcare providers, among others

# Key Informant Feedback on Needs

## Other Services Often Needed

- Mental health support for grandchildren who have experienced trauma
- Respite care for grandparents overwhelmed by their sudden primary parenting role
- Housing, especially for those who live in small spaces
- Parity of stipends between guardian and foster care grandparents
- Employment support
- State assistance for affordable and accessible childcare
- Interaction with school systems, e.g. Individualized Education Program (IEP)

*“Having stable childcare is a big one – regardless of grandparent employment status.”*

# Focus Groups



# Summary of Focus Group Approach

- **Format:** Four 90-minute groups conducted between May 6-9, 2019
- **Purpose:** To collect information on grandparent experiences in raising grandchildren and desired state supports
- **Location selection:** Urban/rural communities, high opioid use disorder rates, racial/ethnic diversity
- **Locations:** Athol, Jamaica Plain, Hyannis, Dorchester
  - May 6, 2019 - 10-11:30am, Athol, MA Family Resource Center
  - May 7, 2019 - 12-1:30pm, Jamaica Plain, MA, MSPCC Office
  - May 8, 2019 – 5:45-7:15pm, Hyannis, MA, Barnstable Senior Center
  - May 9, 2019 – 6-7:30pm, Dorchester, MA, Dorchester Library
- **Structure:** Semi-structured focus group guide including the following domains over the course of 90 minutes:
  - ✓ General caregiving experience
  - ✓ Interaction with state support systems
  - ✓ Blue-sky wishes

*See Appendix for the focus group topic guide.*

# Focus Group Participant Recruitment

- **Recruitment:** Outreach to grandparent support groups
- **Process:**
  - ✓ Recruitment flyer
  - ✓ Confirmation of participation
  - ✓ Focus group with anonymity of responses protected
  - ✓ Thank you notes
- **Demographic form:** Collected anonymous information about the number of grandchildren they are raising, reason for caregiving status, age, race, and gender

# Focus Group Members At A Glance

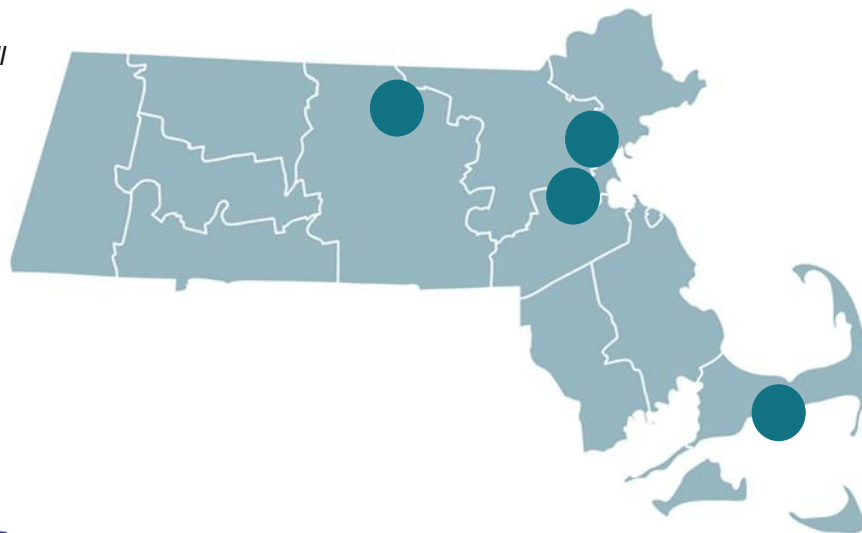
- 36 total grandparents in focus groups
- 8 males, 28 females
- 19 White, 10 African American, 2 White/African American, 1 Other, 4 N/A
- Average age: 64 years old (range 49 - 74)
- Average number of grandchildren being raised per grandparent: 2
- About half of focus group respondents were raising grandchildren due to parental opioid use
- Four had a biological parent present in the household



# Profile Of Focus Group Participants By Site

	Athol	Jamaica Plain	Hyannis	Dorchester
Number of respondents*	6	9	11	7
Average age	61	69	67	58
Average # of grandchildren	1.3	1.7	1.2	2.4
# caregiving due to parent opioids use	2	5	10	2
# of grandparents with parent present	1	1	0	2
Race	6 White	4 African American, 1 West Indian, 3 White, 1 N/A	10 White, 1 White/African American	6 Black, 1 White/African American

*\*Note: There were 36 total participants, but only 33 opted to fill out the optional demographic information form*



# Focus group feedback: Experiences Raising Grandchildren

Quotes from focus group participants:

*“To have my house back to myself”*

*“Sometimes you just do not see the light at the end of the tunnel”*

*“Precisely there is no time at all”*

*“This is digging a hole; it put weight on everything”*

- Strong feeling of responsibility to care for grandchildren
- Caregiving is time consuming and energy-draining
- Struggle between being both a warm-hearted and loving grandparent and a disciplinary caregiver
- Fear for the future

# Focus group feedback: Financial issues

Quotes from focus group participants:

*“Lots of credit cards”*

*“I am using all of my savings”*

*“Jump through hoops”*

*“Living from paycheck to paycheck”*

- Employment status change - Return to work/work more hours
- Receipt of a variety of supports - some received child support, government benefits, and foster care stipends, while others experienced challenges obtaining support
  - Waited 2.5 years for childcare voucher
  - Required legal involvement to obtain Social Security benefits after years of fighting
  - Not enough support
- Identification of extra support:
  - from foundations or supporting institutions for summer camp, respite care, and other services
  - from new resources, including manufacturers coupons and food banks

# Focus group feedback: Relationship Challenges

Quotes from focus group participants:

*“The grandparent really has no rights”*

*“Unification is not everything”*

Grandparents raising grandchildren experience relationship challenges with their grandchildren’s parents

- Emotionally unstable, and lack parenting skills
- Relapses, lack of stability
- Parents have all or most legal rights
- Oppositional intergenerational relationships

# Focus group feedback: Education And Healthcare Decisions

## Education

- Frustration with lengthy IEP (Individualized Education Program) process, especially in rural areas
- Need for advocates to improve grandchild education experience
- Long wait lists for grandchildren to enroll in Head Start

## Healthcare

- Mostly positive experience with healthcare providers and coverage
- Limited providers in rural areas
- Custody paperwork necessary in grandchild's medical care

# Focus group feedback: Grandparent Support Groups

Quotes from focus group participants:

*“Even if our situations are not similar, we are all fighting the fight”*

*“We are all in the same boat”*

- “A life saver”
- Welcoming space, team feeling, strength, information, validation
- Materials/resources such as clothes, holiday items, game nights, trips
- Workshops and referrals

In addition to Grandparent Support Groups, other useful places to go for help include a Family Resource Center, family therapist, friends/co-workers, and schools

# Focus group feedback: Interaction With MA Support System

Quotes from focus group participants:

*“Everything is new to me”*

*“One switchboard, one central source”*

*“...Information has to be clear”*

*“A one-stop shop such as a mental health mall”*

- Limited information on supports; no centralized site (virtual or physical)
- Inconsistent information and supports
- Heavy burden of paperwork and long waiting times for support

# Focus group feedback: Blue-sky Wishes of Grandparents

Quotes from focus group participants:

*“Money tree in the backyard”*

*“Permanent custody should mean permanent custody”*

*“Given them (parents) time to recover and put a time limit on that”*

- Money
- Time
- Knowledge
- Legal supports and resources
- Support addressing parent issues (around recovery or other problems)



# Project Team

## PUBLIC AND PRIVATE HEALTH SOLUTIONS

**Audrey Smolkin, M.P.P.**, Director, Child and Family Policy

**Bittie Behl-Chadha, PhD**, Director, Office of Survey Research

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## ADVISORS

**Colleen Pritoni**, Commission on the Status of Grandparents Raising Grandchildren

**Ilene Mitchell**, Commission on the Status of Grandparents Raising Grandchildren

## Thank you to our Massachusetts sponsors:

The Executive Office of Elder Affairs, Attorney General's Office, the Office of the Child Advocate, our advisors.

# Appendix



# Online Survey of Grandparents and Relative Caregivers



## Survey of Grandparents or Relatives Raising Children

March 20, 2019

### NOTES ON HOW TO READ THIS SURVEY DOCUMENT:

- Text in **BOLD CAPS** in brackets represents programming instructions, which will not be visible to respondents.
- **SP** means “single punch” where only one response is allowed from the list of response options and **MP** means “multi punch” where more than one response can be selected.
- Response options will have radio buttons for the respondent to select; they will not see any question or item numbers.

### GENERAL NOTES FOR PROGRAMMING:

- Include logo for the Commission on the Status of Grandparents Raising Grandchildren on Intro A screen only
- Include progress bar

[INTRO A] [SHOW ALL]

### [Survey of Grandparents or Relatives Raising Children](#)

Thank you for participating in the Survey of Grandparents or Relatives Raising Children being conducted by the Commission on the Status of Grandparents Raising Grandchildren (“the Commission”).

The Commission is conducting this survey to learn more about the roles and needs of grandparents and other relatives who are raising children in Massachusetts with no birth parent present. The information you provide will help the Commission in improving services and promoting more resources for grandparents, relative caregivers, and the children in their care. The information you provide will be kept **private** and **confidential**. Your responses will be grouped with those of other survey participants and the Commission will not see your individual responses. Your participation is greatly appreciated.

[ASK ALL] [SP] [REQUIRE ANSWER] [PROMPT IF LEFT BLANK: Please answer this question to continue with the survey.]

1. A **relative caregiver** is a relative such as a grandparent, aunt, uncle, sister, brother, or other relative who is the primary caregiver for a child instead of the birth parent.

Please confirm that you are currently a relative caregiver for a child under age 18.

1. Yes
2. No

[IF Q1=1 (YES)] [SP] [REQUIRE ANSWER] [PROMPT IF LEFT BLANK: Please answer this question to continue with the survey.]

2. Does a birth parent of the child currently live with you and the child?
  1. Yes
  2. No

[ASK ALL] [SP] [REQUIRE ANSWER] [PROMPT IF LEFT BLANK: Please answer this question to continue with the survey.]

3. Please confirm that you are a resident of the state of Massachusetts.

1. Yes
2. No

[TERMINATE IF Q1=2 (NO) OR Q2=1 (YES) OR Q3=2 (NO)]

Thank you for your time. We are interested in learning about the experiences of Massachusetts grandparents and relative caregivers who are the primary caregiver for a child with no birth parent present, and have no additional questions for you.

[ASK ALL] [SP] [REQUIRE ANSWER] [PROMPT IF LEFT BLANK: Please answer this question to continue with the survey.]

4. For how many children under age 18 are you the primary caregiver, with no birth parent present?

1. 1 child
2. 2 children
3. 3 children
4. 4 children
5. 5 or more children

[SECTION HEADING A] [SHOW ALL]

### [About the Child](#)

[SHOW IF Q4=1]

The next few questions are about the child that you are the primary caregiver for.

[SHOW IF Q4=2-5]

Please answer the next few questions for each child that you are the primary caregiver for, starting with the **oldest** child (“Child 1”) and continue with the next oldest child until you have answered the questions [IF Q4=2-3, PIPE-IN: for all the children in your care] [IF Q4=4-5, PIPE-IN: for the three oldest children in your care].

[LOOP Q5-10 TWICE IF Q4=2] [LOOP Q5-10 THREE TIMES IF Q4=3-5]

[DISPLAY ABOVE Q5]

[SHOW FOR FIRST LOOP]

### [Oldest Child \(Child 1\)](#)

[SHOW FOR SECOND LOOP]

### [Second Oldest Child \(Child 2\)](#)

[SHOW FOR THIRD LOOP]

### [Third Oldest Child \(Child 3\)](#)

[ASK ALL] [SP]

5. What is this child's age?

1. Less than 1 year old
2. 1 to less than 2 years
3. 2 to less than 5 years
4. 5 to less than 10 years
5. 10 to less than 15 years
6. 15 to less than 18 years

[IF Q5 = 1, CODE Q6 = 1]

[ASK IF Q5 IN (2, 3, 4, 5, 6)] [SP] [SHOW RESPONSE OPTIONS LESS THAN OR EQUAL TO ANSWER GIVEN IN Q5]

6. How long have you been the primary caregiver for this child?

1. Less than 1 year
2. 1 to less than 2 years
3. 2 to less than 5 years
4. 5 to less than 10 years
5. 10 to less than 15 years
6. 15 to less than 18 years

[ASK ALL] [SP]

7. Is this child male or female?

1. Male
2. Female

[ASK ALL] [SP]

8. Is this child of Hispanic or Latino origin or descent?

1. Yes, Hispanic or Latino
2. No, not Hispanic or Latino

[ASK ALL] [MP]

9. What is this child's race? *Please select all that apply.*

1. White
2. Black or African American
3. Asian
4. Native Hawaiian or other Pacific Islander
5. American Indian or Alaska Native
6. Other (please specify) \_\_\_\_\_

[ASK ALL] [SP]

10. How are you related to this child?

1. Maternal grandparent
2. Paternal grandparent
3. Great grandparent
4. Aunt or Uncle
5. Sister or Brother
6. Other relative (please specify) \_\_\_\_\_

[SECTION HEADING B] [SHOW ALL]

#### Health of the Child

The next few questions are about the child's health. [IF Q4=2-5 (2 OR MORE CHILDREN), PIPE-IN: We have randomly selected only one child per household. Please think of the [RANDOMLY SELECT 1 CHILD FROM UP TO THREE OLDEST CHILDREN AND PIPE-IN: "oldest child (Child 1)" OR "second oldest child (Child 2)" OR "third oldest child (Child 3)"] that you are the primary caregiver for as you answer the questions.]

[ASK ALL] [SP]

11. In general, how would you rate this child's **physical** health?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

[ASK ALL] [SP]

12. In general, how would you rate this child's **mental or emotional** health?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

[ASK ALL] [MP]

13. Has a doctor, other health care provider, or educator ever told you that this child has any of the following? *Please select all that apply.*

1. Anxiety problems
2. Depression
3. Trauma or stress-related disorder, such as Post-Traumatic Stress Disorder (PTSD)
4. Attention Deficit Disorder (ADD) or Attention Deficit/Hyperactivity Disorder (ADHD)
5. Intellectual disability

6. Learning disability
7. Physical disability that makes it difficult to walk, move or get around
8. Long-term illness, such as asthma, diabetes, etc.
9. Exposed to drugs or alcohol at birth, such as Substance Exposed Newborn (SEN), Neonatal Abstinence Syndrome (NAS), Fetal Alcohol Syndrome (FAS), etc.
10. Other (please specify) \_\_\_\_\_

**[ASK IF Q13=9 (EXPOSED TO DRUGS/ALCOHOL AT BIRTH)] [MP]**

14. Which of the following drugs or substances was this child exposed to at birth? *Please select all that apply.*

1. Alcohol
2. Cocaine
3. Heroin
4. Marijuana
5. Methadone
6. Prescription painkiller or opioid, such as oxycodone, fentanyl, morphine, etc.
7. Subutex/suboxone
8. Other (please specify) \_\_\_\_\_

**[SECTION HEADING C] [SHOW ALL]**

**Supports and Services**

The next few questions are about the types of services and supports you may receive to provide care for this child. [IF Q4=2-5 (2 OR MORE CHILDREN), PIPE-IN: As a reminder, please think of the PIPE-IN: (SAME AS SECTION B) “**oldest child (Child 1)**” OR “**second oldest child (Child 2)**” OR “**third oldest child (Child 3)**”] that you are the primary caregiver for as you answer the questions.]

**[ASK ALL] [SP]**

15. Which of the following best describes the type of caregiver you are to this child?

1. Informal relative caregiver (not involved with any court, Department of Children and Families (DCF), or other authorities)
2. Kinship/foster caregiver involved with DCF
3. Legal guardian
4. Adoptive parent

**[ASK IF Q15=1 (INFORMAL RELATIVE CAREGIVER)] [SP]**

16. Do you have a signed affidavit or other document from this child’s birth parent that allows you to make important decisions on this child’s behalf?

1. Yes
2. No

**[ASK ALL] [MP]**

17. Have you or this child been involved with or received services from any of the following state agencies? *Please select all that apply.*

1. Department of Children and Families (DCF)
2. Department of Developmental Services (DDS)
3. Department of Early Education and Care (EEC)
4. Department of Mental Health (DMH)
5. Department of Public Health (DPH)
6. Department of Transitional Assistance (DTA)
7. Department of Youth Services (DYS)
8. Elder Services
9. *None of the above* [SP]

**[ASK ALL] [MP]**

18. Do you receive financial assistance to care for this child from any of the following sources? *Please select all that apply.*

1. Child support payments from child’s mother through the Department of Revenue (DOR)
2. Informal child support payments from child’s mother
3. Child support payments from child’s father through the Department of Revenue (DOR)
4. Informal child support payments from child’s father
5. [IF Q15=2 OR Q17=1 (DCF)] Monthly foster care stipend from DCF
6. [IF Q15=2 OR Q17=1 (DCF)] Quarterly clothing allowance from DCF
7. [IF Q15=2 OR Q17=1 (DCF)] Birthday bonus stipend from DCF
8. [IF Q15=2 OR Q17=1 (DCF)] Holiday bonus stipend from DCF
9. Social security survivor benefits (SSDI or SSI)
10. Transitional Aid to Families with Dependent Children (TAFDC) or Emergency Aid to the Elderly, Disabled and Children (EAEDC)
11. TAFDC child-only grant
12. Supplemental Nutrition Assistance Program (SNAP)
13. Women, Infants, and Children (WIC) Program
14. Child care voucher from the Department of Early Education and Care (EEC)
15. [IF Q15=2 OR Q17=1 (DCF)] Mileage reimbursement for child’s medical appointments
16. Other (please specify) \_\_\_\_\_
17. *None of the above* [SP]

**[ASK ALL] [MP]**

19. Before taking this survey, were you aware that the following services may be available to assist grandparents and other relatives who are primary caregivers for a child with no birth parent present? *Please select all that apply.*

1. Family Resource Centers
2. Family Caregiver Support Services from Elder Services
3. MassHealth (Medicaid) insurance for child
4. Early Intervention (EI)
5. Special education services (Individualized Educational Plan (IEP) or Section 504 Plan)
6. [IF Q15=2 OR Q17=1 (DCF)] Legal assistance, including legal advice or legal representation
7. [IF Q15=2 OR Q17=1 (DCF)] Child care referral from DCF
8. [IF Q15=2 OR Q17=1 (DCF)] DCF social workers, family resource social workers and other DCF staff
9. [IF Q15=2 OR Q17=1 (DCF)] Help with supervised visits between parent and child
10. [IF Q15=2 OR Q17=1 (DCF)] Transportation assistance to child's medical appointments
11. [IF Q15=2 OR Q17=1 (DCF)] Rise Above Foundation
12. [IF Q15=2 OR Q17=1 (DCF)] Wonderfund Program
13. *None of the above - I am not aware of any resources* [SP]

**[ASK IF ANY ITEM 1-12 SELECTED IN Q19] [MP]**

20. Do you receive any of the following services to assist you in caring for this child? *Please select all that apply.*

[LIST ITEMS SELECTED IN Q19]

**[ASK ALL] [SP]**

21. Are you aware of any support groups in your community for grandparents and other relatives who are primary caregivers for a child with no birth parent present?

1. Yes
2. No

**[ASK IF Q21=1 (YES)] [SP]**

22. Do you currently participate in any support groups for grandparents and other relatives who are primary caregivers for a child with no birth parent present?

1. Yes
2. No

**[ASK IF Q22=1 (YES)] [MP]**

23. Why did you decide to participate in a support group? *Please select all that apply.*

1. To meet other grandparents or relative caregivers
2. To get help or advice from other grandparents or relative caregivers
3. To learn about resources in my area
4. To listen to guest speakers
5. To get out of the house
6. [IF Q15=2 OR Q17=1 (DCF)] DCF makes me go
7. Other reason (please specify) \_\_\_\_\_

**[ASK IF Q22=2 (NO)] [MP]**

24. Why did you decide **not** to participate in a support group? *Please select all that apply.*

1. Not enough time
2. No transportation
3. No child care
4. I don't need support
5. I would be too embarrassed to go
6. I don't want to hear other people's problems
7. Other reason (please specify) \_\_\_\_\_

**[ASK ALL] [GRID: SP ACROSS, MP DOWN]**

25. How interested are you in the following services to assist you in caring for this child? *Please select a response for each item.*

	Very interested 1	Somewhat interested 2	Not at all interested 3
a. Financial resources			
b. Legal assistance (such as help with legal questions, guardianship, finding an attorney, etc.)			
c. Help in working with DCF			
d. Child care, before/after school programs, and summer camps			
e. Finding a support group for myself			
f. Finding a support group for this child			
g. Mental health services for myself			
h. Mental health services for this child			
i. Caregiver respite services			

[ASK ALL] [GRID: SP ACROSS, MP DOWN]

26. To what extent do you agree or disagree with each of the following statements? *Please select a response for each item.*

	Agree completely 1	Agree somewhat 2	Disagree somewhat 3	Disagree completely 4
a. I have the financial means to raise this child				
b. I often feel tired, worn out, or exhausted from raising this child				
c. I have people that I can turn to for help in raising this child				
d. I have a good understanding of the services available to help me raise this child				
e. I feel frustrated with having to provide care for this child				
f. I have taken care of this child for longer than I expected				

[SECTION HEADING D] [SHOW ALL]

Reasons for Raising this Child

The next few questions are about the reasons you are the primary caregiver for this child with no birth parent present. [IF Q4=2-5 (2 OR MORE CHILDREN), PIPE-IN: As a reminder, please think of the PIPE-IN: (SAME AS SECTION B) “**oldest child (Child 1)**” OR “**second oldest child (Child 2)**” OR “**third oldest child (Child 3)**”] that you are the primary caregiver for as you answer the questions.]

[ASK ALL] [MP]

27. Why is this child not living with his or her birth mother? *Please select all that apply.*

1. Mother is deceased
2. Mother doesn't want to take care of child
3. Mother has financial problems or can't afford to keep child
4. Mother is sick
5. Mother has mental health problems (depression, anxiety, etc.)
6. Mother has drug or alcohol problems
7. Mother was abusive/mistreated child
8. Child removed from mother by child protective services
9. Mother is in jail
10. Mother was detained/deported
11. Other (please specify) \_\_\_\_\_

[ASK IF Q27 DOES NOT EQUAL 6 (DRUG/ALCOHOL PROBLEMS)] [SP]

28. To the best of your knowledge, has this child's mother experienced problems with drugs or alcohol?

1. Yes
2. No
3. Don't know/Not sure

[ASK IF Q27=6 (MOTHER HAS DRUG/ALCOHOL PROBLEMS) OR Q28=1 (YES)] [MP]

29. To the best of your knowledge, has this child's mother had problems with any of the following drugs or substances? *Please select all that apply.*

1. Alcohol
2. Cocaine
3. Heroin
4. Marijuana
5. Prescription painkiller or opioid, such as oxycodone, fentanyl, morphine, etc.
6. Other (please specify) \_\_\_\_\_

[ASK IF Q27=1 (MOTHER DECEASED)] [MP]

30. Please select the cause of this child's mother's death.

1. Accident or injury
2. Illness or disease, such as heart disease, cancer, pneumonia, etc.
3. Drug or alcohol use
4. Undetermined
5. Other

[ASK ALL] [MP]

31. Why is this child not living with his or her birth father? *Please select all that apply.*

1. Father is deceased
2. Father doesn't want to take care of child
3. Father has financial problems or can't afford to keep child
4. Father is sick
5. Father has mental health problems (depression, anxiety, etc.)
6. Father has drug or alcohol problems
7. Father was abusive/mistreated child
8. Child removed from father by child protective services
9. Father is in jail
10. Father was detained/deported
11. Other (please specify) \_\_\_\_\_



[ASK IF Q31 DOES NOT EQUAL 6 (DRUG/ALCOHOL PROBLEMS)] [SP]

32. To the best of your knowledge, has this child's father experienced problems with drugs or alcohol?

1. Yes
2. No
3. Don't know/Not sure

[ASK IF Q31=6 (FATHER HAS DRUG/ALCOHOL PROBLEMS) OR Q32=1 (YES)] [MP]

33. To the best of your knowledge, has this child's father had problems with any of the following drugs or substances? *Please select all that apply.*

1. Alcohol
2. Cocaine
3. Heroin
4. Marijuana
5. Prescription painkiller or opioid, such as oxycodone, fentanyl, morphine, etc.
6. Other (please specify) \_\_\_\_\_

[ASK IF Q31=1 (FATHER DECEASED)] [MP]

34. Please select the cause of this child's father's death.

1. Accident or injury
2. Illness or disease, such as heart disease, cancer, pneumonia, etc.
3. Drug or alcohol use
4. Undetermined
5. Other

[SECTION HEADING E] [SHOW ALL]

[About You](#)

The last few questions are about you.

[ASK ALL] [SP]

35. In general, how would you rate your **physical** health?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

[ASK ALL] [SP]

36. In general, how would you rate your **mental or emotional** health?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

[ASK ALL] [SP]

37. Do you have a physical disability that makes it difficult to walk, move or get around?

1. Yes
2. No

[ASK ALL] [SP]

38. What is your age?

1. 18 to 24
2. 25 to 34
3. 35 to 44
4. 45 to 54
5. 55 to 64
6. 65 or older

[ASK ALL] [SP]

39. Are you male or female?

1. Male
2. Female

[ASK ALL] [SP]

40. What is your marital status?

1. Single, never married
2. Unmarried partner
3. Married
4. Widowed
5. Divorced
6. Separated

[ASK ALL] [SP]

41. Are you of Hispanic or Latino origin or descent?

1. Yes, Hispanic or Latino
2. No, not Hispanic or Latino

[ASK ALL] [MP]

42. What is your race? *Please select all that apply.*

1. White
2. Black or African-American
3. Asian
4. Native Hawaiian or other Pacific Islander
5. American Indian or Alaska Native
6. Other (please specify) \_\_\_\_\_

[ASK ALL] [SP]

43. What is the highest grade or level of school that you have completed?

1. 8th grade or less
2. Some high school, but did not graduate
3. High school graduate or GED
4. Some college or 2-year degree
5. 4-year college degree
6. More than 4-year college degree

[ASK ALL] [SP]

44. Have you worked for pay in the last 12 months?

1. Yes
2. No

[ASK IF 44=1 (YES)] [SP]

45. Are you currently working at a job for pay?

1. Yes
2. No

[ASK ALL] [SP]

46. Which region of the state do you live in?

1. Boston/Metro Boston
2. Central
3. Northeast
4. Southeast
5. West

[INSERT STANDARD CLOSING]

Thank you for taking the time to complete this survey.

# Key Informant Interview Guide

# Semi-Structured Interview Protocol

## Introduction:

As you know, UMASS Medical School is conducting a study to examine the number of grandparents raising grandchildren due to opioids use in Massachusetts. Let's refer this population as "the Study Grandparents". The overall goals of the study are to: 1) provide an estimate of the number of individuals in the commonwealth raising grandchildren because 1 or both parents are addicted to an opioid drug or other substances; 2) to document resources, services and supports available to grandparents; 3) to determine whether such services and supports are coordinated in a manner and to identify gaps in services; and 4) to shed light on the experiences, challenges and unmet needs of grandparents raising grandchildren.

You have been selected as a key informant interview to help us obtain information on this subject. We would like to ask you some questions to understand the population, known services gaps and needs of the population, key challenges and successes in addressing the population needs, and possible future approaches to address the needs of Grandparents. We also hope the interview with you today will help us determine other prospective interviewees and inform the next steps of our study.

Do you have any questions before we start?

[Allow interviewee to raise any questions s/he has before the interview start.]

To help us more precisely capture the information, we would like to ask for your permission to record this interview. Do we have your permission to do so?

[Let interviewee respond.]

[If his/her answer is Ok] Ok, thank you! We will now start the interview.

[If his/her answer is No] Ok, we understand and respect your choice. Now we will start the interview.]

## Interviewee Background

- 1) Please tell us a little bit more your relevant background related to the issue of Grandparents Raising Grandchildren due to Opioids Use.
- 2) Can you describe your agency's mission and activities in addressing the issues related to grandparents raising grandchildren?

## Agency Data

Next, I'd like to ask you for some information about data sources.

- 1) Does your agency maintain a complete record of grandparents who raise grandchildren, whose caregiver responsibility is determined through court decision?
  - a. If so, what data systems did you capture that information? Are the data electronic or paper based? How long have the data been recorded in that data systems? Do your data have any information about how long the grandparents raise grandchildren? Any possibility of knowing the reason of this caregiving relationship, and if so, which field(s)/data item(s) could possibly contain the information?

- b. Can you describe the process of how the data are captured in the system after a court determines the GP will be responsible for grandchild? What lag of data recording could there be?
  - c. [Probe] Do you see any risk of not recording the complete set of the Study Grandparent? If not, why? Can you provide us some examples?
- 2) What other agency data can there be to help us gather a complete set of grandparents who raise grandchildren? Can you share any information that you data?
- 3) What is the process of acquiring these data?

## Grandparents Needs and Services

- 1) What are key systems of services that the Study Grandparents may interact with?
  - a. [Probe] What is the pathway for GPs to interact with these systems?
  - b. [Probe] What is each system's role in addressing the needs of the Study Grandparents?
- 2) What do you see as the needs of Study Grandparents related to opioids use?
  - a. What are needs that can be addressed by your agency?
  - b. What are the needs that can only be addressed by other state offices/agencies/departments?
  - c. What are the needs that can be addressed by multiple agencies jointly and have been addressed in the past?
  - d. What are the needs that can be addressed by multiple agencies jointly and have NOT been addressed in the past?
- 3) What challenges do you see the Study Grandparents have to receive financial, social, and other services and supports?
  - a. [Probe] What are the most challenging areas?
  - b. [Probe] What do you see as the most feasible solutions to address these challenges?
- 4) What opportunities do you see to build a stronger and broader support systems for the Study Grandparents, either within your office/agency or across state offices/agencies?
- 5) Before the end of this state fiscal year, will your office/agency run any events geared toward grandparents who raise grandchildren?
- 6) Before the end of this state fiscal year, are you aware of any events that are geared toward grandparents who raise grandchildren?
- 7) What could be barriers for states agencies to address the needs of the Study Grandparents?

## Initiatives at National and at Other States Addressing Grandparents' Needs and Services

- 1) What could be federal facilitators to address the services needs and gaps of the Study Grandparents, including those in Massachusetts?
  - a. [Probe] How can these facilitators be turned into real legislative and policy actions at state-level to support this group?
- 2) What other non-governmental entities are key players in impacting the Study Grandparents?
  - a. [Probe] What are known initiatives provided by these entities in the past?
  - b. [Probe] Are you aware of any planned initiatives to address the needs of the Study Grandparent?
- 3) Are you aware of any other states' initiatives in capturing and/or addressing the Study Grandparents?
  - a. If so, can you elaborate them?
- 4) What are the key successes and lessons learned to address the needs of Study Grandparents that you are aware of?

Thank you very much! This concludes our interview data. We really appreciate your time. If you have any additional comments or questions about our study, please feel free to reach out to me.

# Focus Group Topic Guide



## Semi-structured Grandparent Focus Group Scripts and Questions

### Open Statement and Introduction (8~ mins)

Hi all,

I am [INSERT NAME] from UMASS and will be the facilitator of today's focus group. Also joining me from UMASS is [INSERT NAME].

The study fact sheet provides you with a brief overview of why we are having this meeting. The Commission on the Status of Grandparents Raising Grandchildren (aka the Grandparent Commission) and other state partners are conducting a study to learn more about the roles, experiences, and needs of grandparents (and other relatives) who are raising children under the age of 18 in Massachusetts. The study is particularly concerned about grandparents who are caregiving with no birth parent present and/or birth parent(s) who may have used opioids. The study will help the Commission understand the gaps in services and supports so that we can improve them. This focus group is one of many data sources that we are using to understand grandparent experiences.

Thank you all for volunteering and taking the time to speak with us about your experience as caregivers of your grandchildren. We appreciate your time and input and look forward to hearing your thoughts about your roles and needs as caregivers. Before we begin the focus group, I just want to emphasize a few things.

We want to emphasize that this is an open forum and a safe space to discuss all concerns that you may have for any of the questions we will be asking. The information you share with us today will be anonymized, summarized, and shared with the Commission on the Status of Grandparents Raising Grandchildren and the State agencies that we contract with (EOEA, AG, and OCA) in broad, generalized themes. We will not disclose any of your individual names and/or identifiable information in any reports. If you have a question at any time during this focus group, please let us know. There are no right or wrong answers, and we only ask that you listen respectfully to all views that are shared today, even if they differ from yours. Also, you do not need to answer any question you don't want to, and you do not need to answer every question.

As noted before, we expect this session to last about an hour/hour and a half, and we have a lot to cover in that time.

We will be audio recording today's session to capture your thoughts most accurately. If at any time you would like us to turn off the recording, please let us know. We will be sure to remove names before using this information for any of our reporting.

Are there any questions before we begin today's focus group?

[Pause and answer if any question comes up.]

Now, let us begin.

### Focus Group Questions (80 mins~)

#### General Caregiving Experiences (35 mins~)

[Now, go around the circle and have participants introduce themselves.]

- 1) In a minute or so, please tell us a little bit about your overall experiences as a caregiver for grandchildren? How long have you been caregiving for your grandchildren? How many grandchildren are in your care right now?
- 2) What has made you worried or anxious about being a caregiver of your grandchildren? If you had only one minute to talk to someone about the most challenging aspect(s) of being a caregiver of grandchildren, what would you say?  
[Probe] If you want to, in your answer, please tell us briefly about the reasons that you became the caregiver.  
[Probe] How does the reason you became a caregiver influence your experience? (i.e. parents' drug problems/parents' incarceration, parents' death from other cause, etc.)  
[Probe] For those of you who do not have birth parent present to help care for your grandchildren, how would your experiences have been different?
- 3) When you run into a problem while caring for your grandchildren, whom do you usually go to first for help? Why?  
[Probe] Did you find this support/help adequate? Why? Why not?
- 4) What financial resources are you currently using to help with the care of your grandchildren?  
[Probe] Where do you go to get these resources?  
[Probe] How did you find out about these resources? And how easy was it to get these resources?
- 5) What other non-financial resources are you currently using to help with the care of your grandchildren?  
[Probe] Where do you go to get these resources?  
[Probe] How did you find out about these resources? And how easy was it to get these resources?
- 6) In terms of your grandchildren's education, what has your experience been in making decisions for them in this area?  
[Probe] Have you had support, or experienced barriers, from any of the government agencies in this regard? If so, what has your experience been?
- 7) In terms of your grandchildren's medical care, what has your experience been in making decisions for them in this area?  
[Probe] Have you had support or experienced barriers from any of the government agencies in this regard? If so, what has your experience been?

- 8) In trying to access other support services (medical, mental health, or other) for yourself, what has your experience been? What areas do you want more help with?

Interaction with State Support Systems (25 mins~)

Now we'd like to ask you a few things about your experiences in interacting directly with state support systems.

- 9) Are you aware of any government sponsored financial and non-financial supports available to you and/or your grandchildren? (10 mins)  
[Probe, if not covered in responses to the prior question] Do you feel you have a good understanding about the process and whom to contact for these supports?
- 10) Please reflect on a time that you needed to contact a Massachusetts state agency for assistance in the care of your grandchild. Examples of State agencies include Grandparent Commission, Department of Child and Family, Executive Office of Elder Affairs, Dept of Children and Families, Juvenile Court, and Dept of Early Education and Care. What was the reason you contacted this agency? (10 mins)  
  
[Probe] Did you get what you needed from this (or these) contacts? Why or why not?  
[Probe] What did you like about your experience with getting support from this agency/these agencies?  
[Probe] If there was a challenging experience, what was most challenging about it? What would you like to see changes?
- 11) For those of you who have not accessed or used government supports or services, why not? What barriers do you see to accessing services? (5 mins)

Blue-Sky Wishes (10 min~)

- 12) If you could have any supports you wanted to make your situation easier, what would be the top three things you would ask for?

**Closing:**

Thanks everyone for volunteering to share your experiences and perspectives with us. We really appreciate your time and input. If you have any additional comments or questions about our study, please feel free to reach out to me via phone: 508-856-4040 or email: [Aparna.Kachoria@umassmed.edu](mailto:Aparna.Kachoria@umassmed.edu) [this will be written on the board/posted on a wall during the focus group]

If you haven't already, please fill out the optional questionnaire that we handed out at the beginning, thank you!



# Your Mission is Our Mission

Founded in 1999, **Commonwealth Medicine** is the health care consulting and operations division of **UMass Medical School**.

We work with you to **enhance the effectiveness of health and human service programs** to improve **outcomes for vulnerable populations**.



We offer a **comprehensive suite of health care solutions** that support program integrity, improve member health, enhance public programs and foster a high-quality delivery system.



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