Foster Care

Life Course Experiences, Health, and Health Care

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Foster Care Experience Study: Executive Summary

Health Share of Oregon collaborated with the Center for Outcomes Research and Education (CORE) to explore how the foster care experience influences people's lives and their interactions and attitudes about health and health care.

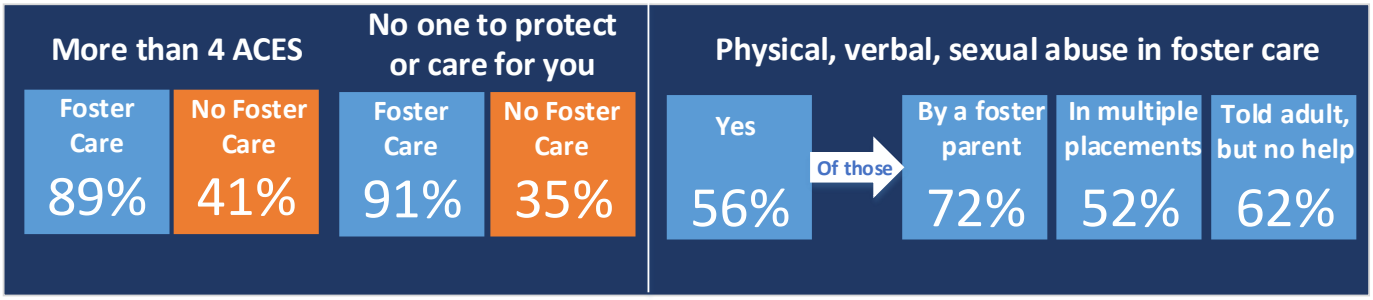
Methods

CORE explored survey data from the Life Course Study (LIFE) – a comprehensive review of life course experiences in Portland, Oregon's Medicaid population – as well as from the Foster Care Experience Survey and Medicaid claims data. In a mixed methods approach, the study team supplemented quantitative data with qualitative interviews with 12 interviewees who were in foster care as children.

Key Findings

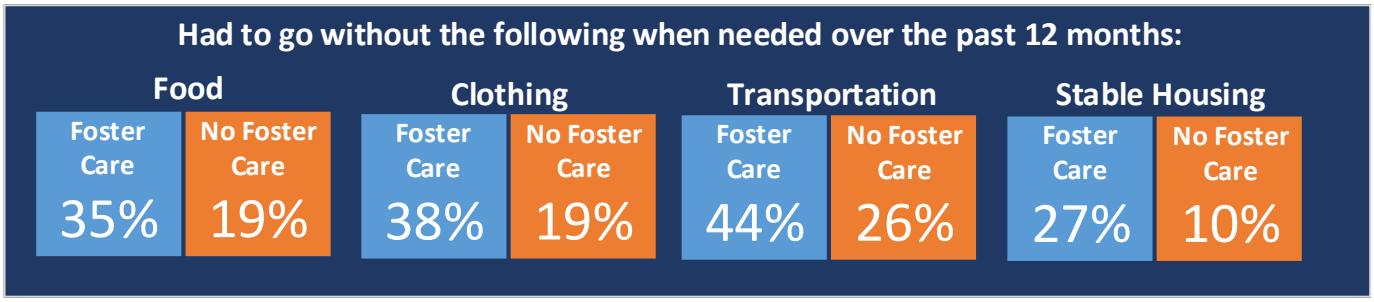
Difficult childhood experiences continued after entering foster care for most.

People with foster care histories were significantly more likely to have difficult experiences in childhood compared to people without foster care history. Approximately 89% had four or more adverse childhood experiences (ACES) and 91% felt they had no one to protect or care for them in childhood. Many that entered foster care continued to face substantial challenges including abuse and instability. Very few felt prepared to be on their own when they left foster care.



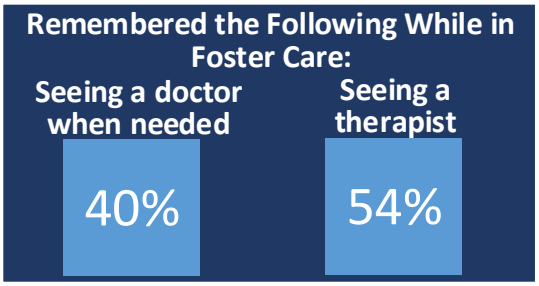
Difficult experiences also continued into adulthood.

People with foster care history were significantly more likely to continue to face difficult experiences in adulthood. While many reported finding and keeping steady work, they still faced significantly more economic insecurity including having to go without needed food, clothing, transportation, and stable housing. People with foster care history also reported more homelessness and verbal abuse by partner/loved one.



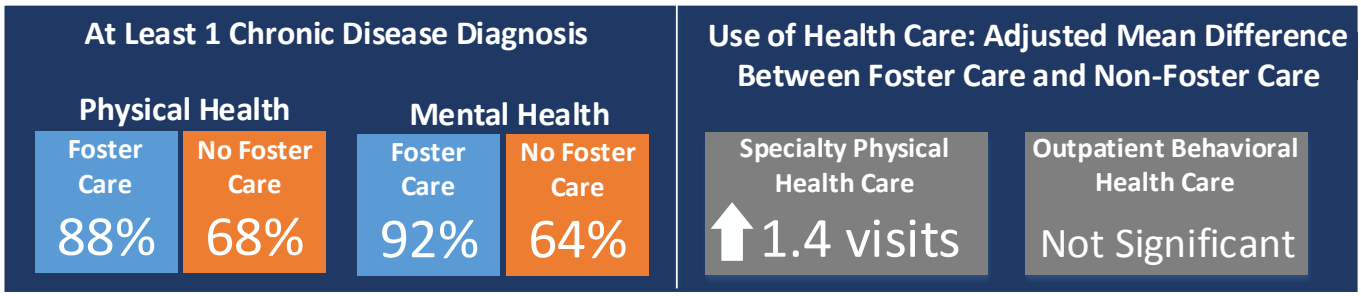
In foster care, access to health services was lacking.

Most people indicated that they were generally healthy while in foster care except for experiences of physical abuse. Some felt that their physical health needs were neglected by foster parents who would not take them to the doctor. In total, only 40% remembered seeing a doctor as often as needed. While we heard about the need for mental health care while in foster care, 54% reported that they remembered seeing a therapist, and our qualitative findings indicated that the care was inadequate and relied heavily on unwanted medication.



Many experienced poor physical and mental health in adulthood; they felt connected to physical health care but NOT mental health care.

People with a history of foster care had worse self-reported health and a much higher prevalence of chronic physical and mental health diagnoses than those without foster care history. While former foster youth tended to have good relationships with physical health providers as adults, they typically avoided mental health care, citing past experiences with over-medication and avoidance of talking about past traumas.



Bottom Line

Foster care is often traumatic and can have a lasting negative impact on an individual's health and experiences through the entire life course. A pattern of experiences emerged from this study – persistent adversity, instability, and unmet mental health needs in childhood and adulthood for Health Share of Oregon members with a history of foster care.

Recommendations for change require systems to come together – from social work to health care – to provide needed care and support in childhood through adulthood.

"I think being in foster care is traumatic. And I think it stays with you for the rest of your life." *- Former Foster Youth*

Recommendations

People with foster care experiences made recommendations for systems change that spanned childhood through adulthood:

- A placement that feels like a home
- Keep siblings together
- More explanation, listening, and empowering of kids while in foster care
- More counseling and talk therapy in foster care
- A supportive network of care
- Peer support or other stable adult support outside of the foster family
- More transitional support when leaving foster care
- Support groups for adults after care

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Acknowledgements

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Introduction

Understanding how foster care influences someone's life and health is essential in driving necessary change in a complicated system. This report presents key findings from an investigation into the life course experiences, health, and health care of a small sample of Health Share of Oregon members who were in foster care during childhood. The research was conducted by the Center for Outcomes Research and Education (CORE) in collaboration with Health Share of Oregon.

Research Background

Extensive research demonstrates that adverse life course experiences are connected to poor health. In an effort to better understand the impact of adversity across the entire life course, CORE launched the LIFE Course Study (LIFE) – a comprehensive review of life course experiences in Portland, Oregon's Medicaid population. As a result, we identified approximately 150 individuals that had been in the foster care system during childhood. Although those who have been in foster care are known to have had traumatic experiences in childhood, to our knowledge there are no studies that have explored experiences across the full life course for the foster care population. Further, little is known about the specific health care needs of this population and how their life experiences have shaped their use of health care.

Health Share of Oregon's Foster Care Initiative

Health Share of Oregon identifies children in foster care as a priority population as they represent one of the most vulnerable populations in Medicaid. They carry a higher burden of disease, face incredible social complexity, and often experience multiple changes in caregiver. These dynamics contribute to significant health and health care disparities for these children and present unique challenges for health plans and care providers.

Health Share's approach began by ensuring foster kids receive mental, physical, and oral health assessments in a timely manner upon entry into care. That initial effort led to a much broader strategic effort to build coordinated support around children in foster care, with particular attention to children's health needs. Health Share has created a community collaboration involving multiple child serving systems to build a more coordinated system of care for children in foster care.

Objectives

This research was a collaborative effort meant to support Health Share's strategic foster care initiatives by examining experiences, health, and health care for Health Share members with foster care experience. The objectives of this study were as follows:

1. **To explore the life course experiences of individuals with foster care history.**
   We used results from our LIFE survey, a comprehensive survey of experiences from childhood through adulthood, and our Foster Care Experiences Survey, to understand patterns of life course experiences for Health Share members with and without a history of foster care.

2. **To assess the health and health care use for individuals with foster care experience.**
   We used quantitative and qualitative methods to assess health and health care while in foster care and in adulthood. Outcomes included subjective measures of health and access to care, physical and mental health diagnoses, and health care utilization.

3. **To explore systems change recommendations from individuals with foster care experience.**
   We interviewed study participants with foster care experience about their thoughts on needed systems changes and what they think would help improve care and outcomes for people who experience foster care.

Methodology

Overview

This was a mixed methods retrospective study that investigated the impact of foster care in childhood on life course experiences and health outcomes. Differences in key life experiences, health, and health care measures were compared between those with and without foster care experience. For those with a history of foster care, additional descriptive and qualitative analyses were performed to understand the foster care experience and its connection to health, health care, and systems change.

Data

We used four data sources for this study: the LIFE Survey, the Foster Care Experiences Survey, Medicaid claims data, and qualitative interviews.

LIFE Survey	Foster Care Survey	Medicaid Claims	Qualitative Interviews
The LIFE survey measured many experiences including social support, household instability, economic insecurity, and abuse. Experiences were captured in childhood, adulthood, and the present.	The Foster Care Experiences Survey measured experiences in foster care, including questions on placements, school, relationships, health & health care, reasons for exit, and life skill preparedness.	Comprehensive Medicaid claims from Health Share of Oregon included service utilization, diagnoses, procedure codes, and demographic data from 2013 to 2015.	Qualitative interviews explored physical and mental health, health care services, foster care experiences, and systems change.

Survey Development

The LIFE survey was developed from more than 70 interviews, the majority of which were with individuals who had complex medical and psychosocial needs and high use of health care. The Foster Care Experience Survey was developed through an extensive literature review, consultation with experts including Health Share of Oregon's Foster Care Advanced Primary Care network, and cognitive testing with study participants with foster care experience.

The Study Population

For the LIFE survey, we drew a sample of approximately 10,000 Health Share of Oregon members. Using claims data, we oversampled members with higher medical complexity (top 10% of CDPS[1] +Rx risk scores), higher utilization of acute care[2], or who were African American. We received 2,344 completed surveys (Exhibit 1).

A total of 148 (6.3%) LIFE survey respondents reported having been in foster care at some point in their childhood. We sent the Foster Care Experience Survey to all LIFE survey respondents with foster care histories who indicated that they were willing to be contacted again (N=119), and 55 people responded (Exhibit 1).

To get a sample with a variety of foster care experiences and health outcomes for the qualitative interviews, we selected 39 individuals who reported a mix of placement number and self-reported health (Exhibit 2). A total of 12 people were successfully recruited and interviewed.

Exhibit 1. Study Sample

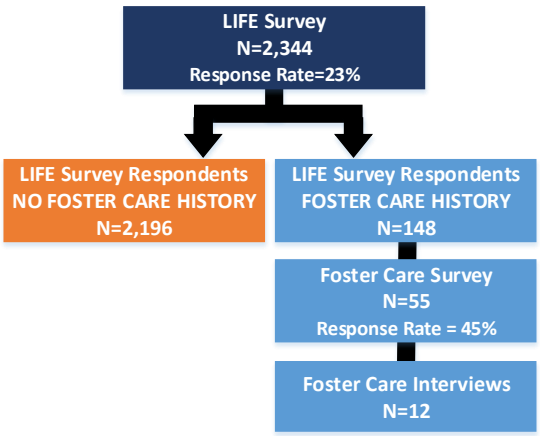


Exhibit 2. Foster Care Interview Sample

• 3 placements or less • Good health	• More than 3 placements • Good health
• 3 placements or less • Poor health	• More then 3 placements • Poor health

1. CDPS + Rx =Chronic Illness and Disability Payment System, a claims-based algorithm that scores members based on chronic medical conditions, demographics, and prescription patterns
2. Three or more emergency department visits, two or more inpatient events, or one inpatient event AND two or more emergency department visits during the last year

Demographics

LIFE survey respondents with foster care history had similar demographics as respondents without foster care history. The age and race distributions between the foster care and non-foster care LIFE respondents were comparable; approximately half were over the age of 50, and slightly over two-thirds self-reported as white. Respondents with a history of foster care experience were slightly more likely to be female (Exhibit 3).

The respondents to the Foster Care Experiences Survey were slightly older, and more likely to self-report as white and female, compared to the LIFE respondents from which they were selected.

Exhibit 3. Overview of Demographics[1]

	LIFE Survey Sample				Foster Care Survey Sample	
	No Foster Care N=2196		Foster Care N=148		Foster Care N=55	
	N	%	N	%	N	%
Age						
30 and under	255	11.6	23	15.5	5	9.3
31-40	363	16.5	15	10.1	5	9.3
41-50	410	18.7	27	18.2	10	18.5
51-60	644	29.3	51	34.5	23	42.6
Over 60	504	23.0	31	21.0	11	20.4
Female	1358	61.8	101	68.2	40	74.1
Race						
White	1477	67.3	101	68.2	43	79.6
Black	283	12.9	21	14.2	6	11.1
Other	367	16.7	24	16.2	5	9.3
Hispanic	184	8.4	11	7.4	4	7.4

1. Categories are mutually exclusive. Percentages do not add to 100% as missing data category not included.

Analysis

LIFE Survey

We calculated the prevalence of key life experiences – social support, school experiences, household instability, economic insecurity, and abuse – in both childhood and adulthood. We used weighted chi-square tests to assess the statistical significance of differences in prevalences between our foster care and non-foster care respondents.

Foster Care Experiences Survey

We calculated descriptive statistics of foster care experiences – including frequency and type of placements; support, neglect, and abuse while in foster care; health and health care use; and readiness to exit foster care – for the 55 individuals who answered the Foster Care Experiences Survey.

Claims

We used regression models adjusted for age, sex, race, and ethnicity, to assess differences in the prevalence of various diagnosed chronic physical and mental health conditions between LIFE respondents with and without a history of foster care. Chronic conditions were identified from ICD-9 codes and had to appear twice in the two year look back period to be counted. We also estimated the adjusted differences in per member per year rates of health care utilization across a number of domains – including primary care, behavioral health services, emergency department visits, and inpatient stays – between the two groups. For the utilization analysis, we trimmed outliers above the 99 percent level to mitigate the influence of these extreme cases.

Qualitative Interviews

We conducted qualitative interviews in person or over the phone with 12 study participants, representing the four sample groups equally (Exhibit 2). Each interview was audio recorded and transcribed by Type4Me. Interview transcripts were loaded into ATLAS.ti software and coded by topic including physical health, mental health, and systems change. A team of five researchers reviewed results and identified major themes within this coding schema.

Objective 1.1 Life Experiences – The LIFE Survey

Key Findings

- When reflecting back on childhood, survey respondents with foster care experience were significantly more likely to report having negative school experiences, instability in their household, and abuse and maltreatment than respondents who were not in foster care. They were also less likely to report having had social support than those who were not in foster care.
- In adulthood, respondents with a history of foster care reported similar social support, but were significantly more likely to report economic insecurity compared to those without a history of foster care.

What We Did

We used LIFE survey data to examine and compare self-reported experiences from childhood, adulthood, and the present between individuals who reported a history of foster care and those who did not. We used sample weights to correct for the oversampling of our study design and to account for non-response bias.

Results

Childhood Experiences

Overall, survey respondents with foster care experience were significantly less likely to report having social support, and more likely to report negative school experiences, instability in their household, and abuse in childhood, than respondents who did not have a history of foster care (Exhibit 4).

Only 60% of people with a history of foster care reported having a family member who made them feel loved, important, or special compared to 94% for those without foster care. More than 50% of people with foster care history dropped out of school compared to about 36% for those without foster care histories. Stark differences were seen in all measured aspects of household insecurity. For example, homelessness was more than three times more prevalent in respondents with foster care histories than in those without. Foster care respondents were twice as likely to report experiencing verbal, physical, and sexual abuse. Only about 2% of foster care respondents reported no adverse childhood experiences (ACEs) compared to around 20% of non-foster care respondents. Conversely, 88% of foster care respondents reported more than four ACEs compared to 40% of non-foster care respondents.

Exhibit 4. Childhood Experiences

	Foster Care	No Foster Care	p-value[1]
Social Support			
Close and supportive relationships with family/friends	76.0%	93.1%	**<0.001**
Close and supportive relationships with other relatives	62.5%	82.9%	**<0.001**
Family member who made you feel loved/important/special	60.8%	94.3%	**<0.001**
Adult, other than parents, who encouraged/supported you	49.1%	80.3%	**<0.001**
School Experiences			
Struggled with schoolwork	63.9%	52.0%	**0.015**
Bullied by peer/classmate	68.5%	53.0%	**0.002**
Dropped out of school	56.85	36.5%	**<0.001**

1. P-value <0.05 considered statistically significant, *ACE questions

Table continued on next page

Exhibit 4. Childhood Experiences (Continued)			
	Foster Care	No Foster Care	p-value[1]
Household Instability			
Times without a regular place to live	67.6%	20.1%	**<0.001**
Times without enough to eat	58.6%	23.6%	**<0.001**
Times when you felt nobody would protect/take care of you	90.8%	35.3%	**<0.001**
Household member depressed, mentally ill, or suicidal*	60.0%	37.0%	**<0.001**
Household member problem drinker/illegal drug user*	65.4%	37.9%	**<0.001**
Household member ever in jail or prison*	39.6%	19.6%	**<0.001**
Parents divorced or separated during childhood*	88.6%	50.0%	**<0.001**
Ever run away from home	65.6%	31.7%	**<0.001**
Abuse			
Household member ever verbally abused you*	66.9%	37.5%	**<0.001**
Household member ever physically abused you*	69.5%	38.1%	**<0.001**
Saw violence between parents/caregivers*	44.4%	26.3%	**<0.001**
Anyone ever sexually abused you*	47.9%	27.1%	**<0.001**
Adverse Childhood Experiences (ACEs)			
No reported adverse childhood experiences	1.7%	22.2%	**<0.001**
More than 4 reported adverse childhood experiences	89.0%	40.6%	**<0.001**

1. P-value <0.05 considered statistically significant, *ACE questions

Adulthood Experiences

By adulthood (19-31+ years), there were fewer differences in reported social support, economic insecurity, and experiences of abuse between survey responses for those with and without a history of foster care; however, some differences remain (Exhibit 5). Although foster care respondents were less likely to report engagement with organized activities during adulthood, this difference was not significant. Likewise, there was no difference in close relationships with others between the two groups. While foster care and non-foster care respondents were equally likely to have found and kept steady work, people with foster care histories experienced much greater prevalence of homelessness. Foster care respondents were also more likely to have experienced verbal abuse by a loved one in adulthood.

Exhibit 5. Adulthood Experiences			
	Foster Care	No Foster Care	p-value[1]
Social Support			
Involved in organized activity such as community groups	41.2%	50.1%	0.074
Close relationships with people you could count on	92.2%	89.0%	0.268
Economic Security			
Find and keep steady work	73.5%	73.2%	0.943
Have trouble affording enough to eat	50.9%	42.8%	0.107
Ever homeless	48.4%	32.6%	**0.002**
Abuse			
Experience physical abuse by a partner/loved one	32.7%	31.0%	0.710
Someone sexually abused you or forced sex against your will	21.3%	15.6%	0.133
Partner/loved one ever verbally abused you	68.1%	55.0%	**0.008**

1. P-value <0.05 considered statistically significant

Current Experiences

Survey respondents were asked about their experiences in the 12 months prior to completion of the survey (Exhibit 6). The majority of social support experiences were similar for both the foster care and non-foster care samples, although significantly fewer people with foster care experience had someone to confide in about their problems.

Differences in economic security remained significant between groups. Compared to non-foster care respondents, foster care respondents were more likely to report having struggled to make ends meet for the entire 12 months previous to filling out the survey. This translated into being almost twice as likely to go without needed food or clothing, and nearly three times as likely to go without stable housing.

Exhibit 6. Experiences in the Past 12 Months

	Foster Care	No Foster Care	p-value[1]
Social Support			
Someone to love and make you feel wanted	92.8%	89.0%	0.196
Someone to give you good advice	92.0%	92.1%	0.978
Someone to get together with for relaxation	88.9%	86.7%	0.499
Someone to confide in about problems	71.5%	89.9%	**<0.001**
Someone to help if you were confined in bed	87.9%	81.9%	0.104
Economic Security			
Struggle to make ends meet			**0.004**
None of the time	34.8%	36.6%	
Some of the time	20.1%	28.0%	
Most of the time	7.0%	12.4%	
All of the time	38.1%	23.1%	
Go without any of the following when needed:			
Food	34.8%	18.9%	**<0.001**
Utilities	14.1%	15.4%	0.721
Transportation	44.3%	26.2%	**<0.001**
Clothing	38.3%	19.8%	**<0.001**
Stable housing	27.4%	9.8%	**<0.001**
Medical Care	17.8%	12.3%	0.107

1. P-value <0.05 considered statistically significant

Objective 1.2 Life Experiences – the Foster Care Experiences Survey

Key Findings

- The most common reasons for entering foster care were physical and emotional neglect.
- Most respondents were in foster care for multiple years, had multiple placements, and had to switch schools.
- Few respondents felt loved and protected while in foster care, and over half experienced physical, verbal, or sexual abuse in foster care. The perpetrator of the abuse was most often a foster parent; over half reported that the abuse occurred at more than one placement; and 61.5% said they tried to get an adult to help but the adult did nothing.
- Most exited foster care because they aged out or ran away, and very few felt completely prepared to be on their own.

What We Did

We developed an in-depth survey of foster care experiences – the Foster Care Experiences Survey – and sent it to 119 LIFE survey respondents who had indicated having a history of foster care. The survey included questions about foster care entrance and placements; love and neglect in foster care; abuse in foster care, and exiting foster care. We received 55 surveys and conducted descriptive analyses of the responses.

Results

Foster Care Entrance and Placements

The majority of respondents reported entering foster care due to abuse or neglect (40% and 38%, respectively). Most (72%) were in foster care for three or more years, and 11% were in for more than 10 years. Just under 20% reported only having one placement, while 23% had 7 or more placements. Most respondents (83%) were placed with strangers instead of kinship or group care and 75% had to switch schools due to foster care.

Love and Neglect in Foster Care

About half of the survey respondents reported that they felt protected, had positive relationships with foster families, or had felt loved while in foster care at "some" of their placements; 34% reported that they felt loved at "none" of their placements. Emotional neglect occurred at "some" placements for 44% of respondents. Physical neglect occurred but was less prevalent; over half reported not experiencing physical neglect at any of their placements (Exhibit 7).

Exhibit 7. Experiences in Foster Care[1]

How many placements did you experience the following?	All	Some	None
Feeling protected and well cared for by your foster family or families	21.3%	51.1%	27.7%
Positive relationships with your foster family or families	22.4%	53.1%	24.5%
Feeling loved by a foster parent or caretakers	18%	48%	34%
Emotional neglect, or having your foster family fail to notice or respond to your feelings	28%	44%	28%
Physical neglect, or having your foster family fail to meet your basic needs such as food or clean clothes	22.4%	22.4%	55.1%

1. Percentages do not include missing values

Abuse in Foster Care

Over half of respondents reported that they experienced verbal, physical, or sexual abuse while in foster care (Exhibit 8). Of those that reported abuse at a foster care placement (N=29), the perpetrator of abuse was most often the foster parent (72.4%), the second most prevalent perpetrator was another foster child (34.5%). For 51.7% of respondents the abuse happened in more than one placement, and 61.5% reported telling an adult about the abuse and the adult not doing anything to help.

Exiting Foster Care

Respondents exited foster care in a variety of ways. The most common reason (35%) was aging out, while 25% ran away and 25% returned to their original family. Of those who did not return to their original family (N=45), only 10% reported that they felt "completely prepared" to be on their own, and almost half said they were not prepared at all. Only half received support, and the types of support they received varied. (Exhibit 9). Very few respondents reported having positive relationships with foster or original families after leaving foster care (data not shown).

Bottom Line: Objective 1

People with foster care histories experience lifelong adversity. They were significantly more likely to have difficult experiences in childhood compared to people without foster care history. Many that entered foster care continued to face substantial challenges in childhood. In adulthood, people with foster care histories were still significantly more likely to face greater social challenges than those without foster care histories, including economic insecurity and homelessness.

Exhibit 8. Experiences of Abuse [1]

While you were in foster care, did you ever experience any verbal, physical, or sexual abuse?	
Yes	55.8%
Who abused you?[2, 3]	
Foster parents	72.4%
Foster peer	34.5%
Child of Foster parents	20.7%
Staff	10.3%
Someone else	20.4%
Did the abuse happen in more than one placement?[3]	
Yes	51.7%
Did you tell an adult about the abuse?[3]	
Yes, tried to help	3.8%
Yes, didn't do anything	61.5%
No	34.6%

1. Percentages do not include missing; 2. Mark all that apply; 3. N=29, skipped people who did not report abuse

Exhibit 9. Experiences Exiting Foster Care[1]

Age when you left foster care?	
Age (years)	15.7
Why did you leave foster care?	
Returned to original family as child	25.0%
Adopted	12.5%
Aged out	35.0%
Ran away	25.0%
Guardianship	2.5%
When you left foster care, did you feel prepared to be on your own?[2]	
Completely prepared	10.0%
Somewhat prepared	32.5%
Not at all prepared	47.5%
Not sure	10.0%
As you were leaving Foster care, did you receive support?[2]	
Yes	50.0%
No	50.0%
As you were leaving foster care, did you receive any of the following kinds of help or support?[2]	
Money/budgeting	20.0%
School support	20.0%
Housing assistance	17.1%
Job training	20.6%
Mentoring	9.1%

1. Percentages do not include missing; 2. N=45, skipped people who returned to original family

Objective 2.1 Health & Health Care in Foster Care – Quantitative

Key Findings

- Most Foster Care Experience Survey respondents indicated that they were generally healthy while in foster care, but only 40% reported seeing a doctor as often as needed.
- About half recalled seeing a mental health therapist or counselor and many were diagnosed with a behavioral or mental health condition that they did not agree with.
- Approximately 40% remember being medicated as part of their mental health treatment.

What We Did

We conducted descriptive analyses on responses to the Foster Care Experiences Survey, focusing on questions about physical health, mental health, and access to health care while in foster care.

Results

Physical Health

The majority of survey respondents (62%) indicated that they were "often" healthy while they were in foster care; however, only 40% felt like they saw a doctor as often as they needed (Exhibit 10).

Mental Health

Only about half of survey respondents remembered seeing a therapist or counselor while they were in foster care, and about half remembered being told they had a behavioral or mental health condition. Of those that received a diagnosis (N=25), 44% indicated that they did not agree with the diagnosis, and 41% remembered receiving medication for their mental health care (Exhibit 10).

Exhibit 10. Health & Health Care in Foster Care[1]

How often would you say you were generally healthy?	
Often	62.3%
Sometimes	34%
Never	3.8%
Do you feel like you saw a doctor as often as you needed?	
Yes	39.6%
No	28.3%
I don't remember	32.1%
Did you see a therapist or counselor?	
Yes	53.7%
No	31.5%
I don't remember	14.8%
Were you told by a doctor or health care worker that you have a behavioral or mental health condition?	
Yes	48.1%
No	32.7%
I don't remember	19.2%
Did you agree with the diagnosis?[2]	
Yes	52%
No	44%
I don't remember	4%
Did you receive medication to treat your behavioral/mental health condition?[2]	
Yes	41.4%
No	44.8%
I don't remember	13.8%

1. Percentages do not include missing; 2. N=25, skipped people who did not receive a behavioral or mental health diagnosis

Objective 2.1 Health & Health Care in Foster Care – Qualitative

Key Findings

- Interviewees believed that they were generally healthy during foster care, except at times when they experienced severe physical abuse.
- Access to physical health care was a challenge for some because their health needs were sometimes neglected by foster parents or foster parents did not want providers to discover signs of physical abuse.
- Many interviewees reported substantial mental health needs that may have stemmed from their persistent traumatic experiences and isolation.
- Many felt that their mental health care was inadequate in foster care and relied too heavily on medication and less on therapy and counseling.

What We Did

We interviewed 12 individuals who responded to the Foster Care Experiences Survey to learn more about their self-reported physical and mental health needs and self-reported use of health care while in foster care. To get a mix of foster care experiences and health, we selected people based on number of placements and self-reported health (see Exhibit 2, page 5). This population was particularly difficult to recruit for an interview, and because of this, those we did interview may not be representative of the population as a whole. We analyzed the interviews to identify overarching themes.

Results

Physical Health in Foster Care

Generally Healthy in Childhood, Besides Physical Abuse. Most participants reported that they were fairly healthy as children, with a few recalling that they had chronic minor health issues such as repeat sinus infections and allergies. However, some of the participants recalled experiences of physical abuse in foster care that left them with substantial physical injuries.

Physical Health Care Neglected for Some. Although most reported being healthy, access to care was a challenge. Some reported not having an established primary care physician or regular health care visits, and others reported that their health care was neglected, while in foster care. For example, one participant recalled burning herself severely and being in so much pain that she vomited, yet her foster parents refused to take her to a health care provider for treatment. One participant said she did not attend regular visits with health care providers to keep them from seeing bruises and other injuries from the physical abuse she endured at the hands of her foster parents. For those who did see a doctor, several reported that they felt their providers were more interested in accomplishing the task of the health care visit than genuinely caring for them as a patient.

IN THEIR OWN WORDS:

"As far as I know, I was healthy…I don't remember ever going to a hospital or doctor."

"I think that my physical health was probably a little bit neglected."

"I had braces. That's one thing I did get done. One of the -- foster moms did make sure that I got braces. That was pretty amazing."

"You get your [butt] kicked a lot. You have bruises and stuff, they don't want to take you to the doctor."

"I burned the back of my legs really bad. It was so painful. I ended up throwing up. I was in track [and field] and the coach said that I should see a doctor about my burns, but I never got to."

"I didn't feel like they [the provider] cared, I feel like they just wanted to get their job done."

Mental Health in Foster Care

Trauma and Isolation in Foster Care. For many interviewees, experiences in foster care were additional trauma on top of the existing trauma they endured with their original families.

Many of the participants were separated from their siblings, which they described as traumatizing and isolating. Several participants stated that this had lifelong consequences for their relationships, and many believed that they were not as close to their siblings as they might have been had they remained together.

In addition to being cut off from their siblings, many participants struggled to make and keep friendships while in foster care. This was due in part to frequent moves, especially for those who switched schools often.

Several participants recalled how they felt alone, unwanted, and unloved while in foster care. Others purposely isolated themselves to avoid being hurt by people. Many of the participants revealed that they had attempted suicide while in foster care.

Inadequate Mental Health Care and Too Much Medication. The interviewees generally did not feel that they received sufficient mental health therapy or counseling while in foster care, and most wished they had been provided more mental health treatment, specifically talk therapy. Many felt that talk therapy with a consistent therapist would have provided them with an outlet to process and understand their past and present experiences. Private, individual therapy would have also allowed for a safe space to disclose any abuse or neglect that they were experiencing at the hands of their foster parents or caregiver staff.

Instead of counseling or talk therapy, participants felt that the majority of their childhood mental health treatment was medication-based, and many participants had bad experiences with these treatments as children. Many felt that this medication had been forced upon them.

IN THEIR OWN WORDS:

"A lot of foster parents told me when I was younger, 'Oh, you're getting beat with a jump rope because you are bad… you're worthless… your mom and dad didn't want you.' Those are the kinds of things that you hear."

"Because there were five of us, we couldn't all go together. So they split us up… that was very hard. Very hard. Because you know, we miss our siblings so badly. And although it was necessary for us, it was really devastating."

"I just remember crying and saying nobody loved me."

"I had a hard time making friends with people because I knew I was going to be moved around a lot."

"I probably should've gone through more counseling than I did. Because I was so angry. I shut everybody out."

"I was suicidal. I tried to kill myself twice while I was in foster care…it was like 'let's see what drugs we can put her on.' It was more forced. I didn't really feel like I had a choice in it."

"The only time I really got medical care was when I tried to kill myself."

"I felt like I fell through the cracks…my case worker told me all the time 'well, I've got all these other cases I'm working on'…. But 'you're not at the top of my list,' is what I heard. So I think it -- it might've been beneficial at least to have a -- more support, not just a psychiatrist shoving pills down my throat, but having like an actual counselor or a doctor."

Objective 2.2 Health & Health Care as an Adult – Quantitative

Key Findings

- Respondents with a history of foster care had worse self-reported physical and mental health and much higher prevalence of chronic physical and mental health conditions compared to those without foster care histories.
- The greatest disparity was in diagnosed mental health conditions. Despite this, we found similar use of mental health care between groups.
- Use of primary care and the emergency department was also comparable between foster care and non-foster care respondents, but we found significantly increased use of specialty and inpatient physical health care, which may be due to the increased physical health burden.
- These results suggest that respondents with a history of foster care may be engaging in health care to meet their physical health needs, but not their mental health needs.

What We Did

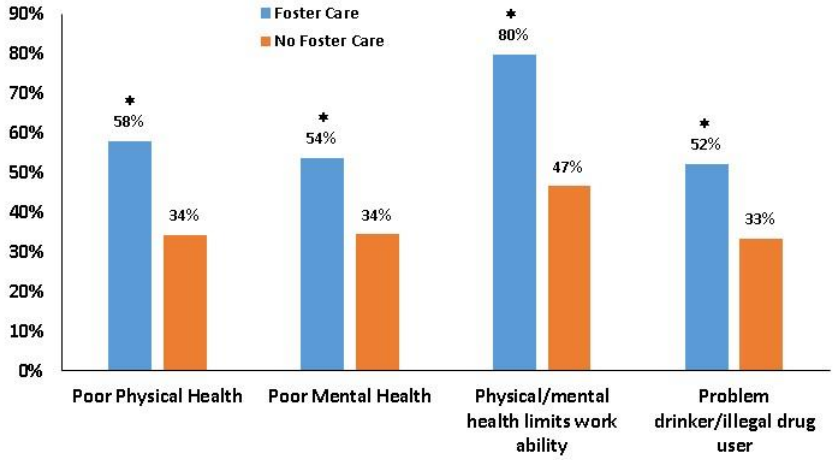
Health and health care outcomes were explored through LIFE survey responses and Medicaid claims data. We compared self-reported health and objectively-measured diagnoses and health care utilization between individuals with and without foster care histories. We used sample weights to correct for the oversampling of our study design and to account for non-response bias. Due to the 42CFR part 2 regulations of the use of substance use data, we were unable to examine substance use diagnoses or treatment in the claims data, but did examine self-reported problems with drinking/drug use from the LIFE survey.

Results

Self-Reported Health

Individuals with foster care histories had a significantly higher prevalence of self-reported "fair" or "poor" physical and mental health, compared to those without foster care histories (Exhibit 11). After adjusting for age, sex, race, and ethnicity, foster care respondents had 1.80 greater odds of reporting fair or poor physical health, and 1.46 greater odds of reporting fair or poor mental health. People in foster care also reported significantly higher rates of having their physical/mental health limit their ability to work and problem drinking/drug use (Exhibit 11).

Exhibit 11. Self-Reported Health



*Statistically significant difference between foster care and non-foster care groups, p<0.05

Chronic Physical & Mental Health Diagnoses

Using Medicaid claims data, we examined diagnoses of chronic physical and mental health conditions over two years for LIFE survey respondents with and without self-reported foster care histories. Over 87% of respondents with foster care histories have a chronic physical health diagnoses, chronic mental health diagnoses, or both. After adjusting for socio-demographic factors including age, race, and gender, individuals with foster care histories had significantly greater risk of having a physical health condition, mental health condition, or both (Exhibit 12).

Exhibit 12. Prevalence of Chronic Physical & Mental Health Diagnoses				
	Foster care	No Foster care	RR[1]	P-value[2]
At least one physical health diagnosis	88.1%	67.6%	**1.3**	**0.042**
At least one mental health diagnosis	91.6%	64.6%	**1.6**	**<0.001**
Physical & mental health diagnosis	87.9%	59.9%	**1.7**	**<0.001**

1. RR=Relative Risk, adjusted for age, race, & sex; 2. P-value <0.05 considered statistically significant

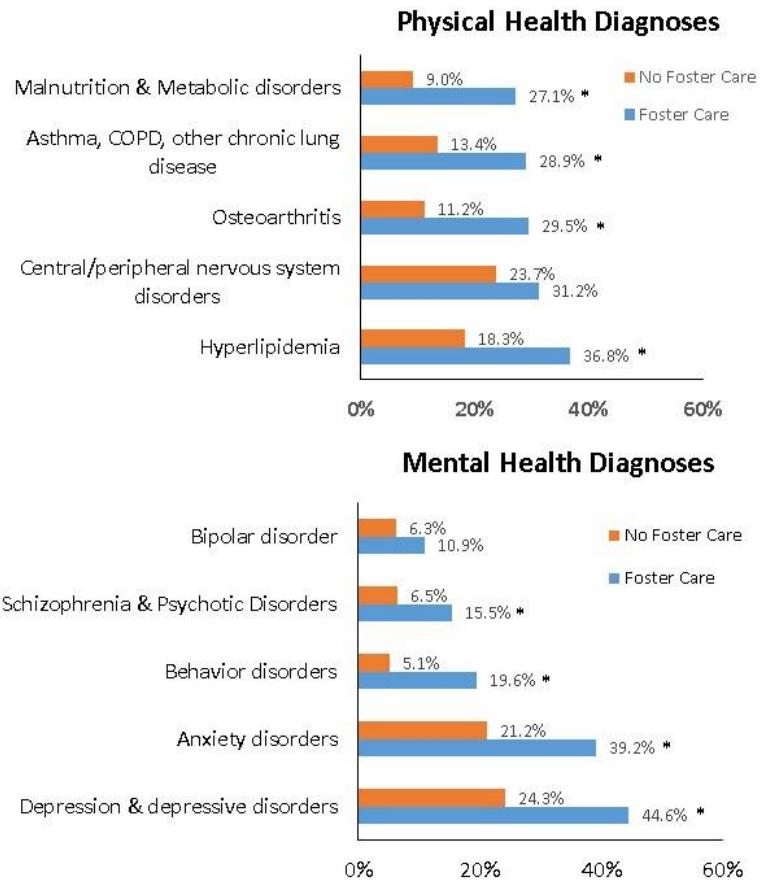
Specific Physical & Mental Health Diagnoses

All but one of the top five physical and mental health conditions were significantly more prevalent in the foster care history group (Exhibit 13). Depression and anxiety were the most prevalent conditions among foster care individuals overall. Behavior disorders were almost four times more prevalent in the foster care group compared to the group without foster care.

Utilization of Health Care

To understand patterns of health care use between groups, we measued the average per member per year usage of multiple domans of health care. We found comparable use of primary care and the emergency department (Exhibit 14); however, LIFE survey respondents with foster care history had significantly increased use of specialty and inpatient care. The increased use of this kind of care may reflect the high prevalence of physical health conditions – some of which may require specialty and/or inpatient care. In contrast to the significantly greater mental health burden experienced by indivuals who were in foster care, there was comparable use of both outpatient and inpatient mental health (Exhibit 14).

Exhibit 13. Physical & Mental Health Diagnoses



*Statistically significant difference between foster care and non-foster care groups, p<0.05; Note: Anxiety includes diagnosis of post-traumatic stress disorder

Exhibit 14. Utilization of Health Care Per Member Per Year (PMPY)[1]				
	Foster care	No Foster care	Adj. Mean Diff.[2]	p-value[3]
Primary care provider	3.7	3.2	0.17	0.702
Specialty Physical Health	4.3	2.6	1.43	**0.003**
Emergency Department	0.8	0.6	0.19	0.123
Non-obstetric inpatient	0.2	0.09	0.12	**0.002**
Outpatient behavioral health	2.4	1.4	0.94	0.120
Inpatient behavioral health	0.005	0.005	0.00	0.951
Pharmacy	35.8	27.6	1.51	0.695

1. Outliers above 99th percentile were removed; 2. Difference adjusted for age, sex, race, ethnicity; 3. p<0.05 considered significant

Objective 2.2 Health & Health Care as an Adult – Qualitative

Key Findings

- Interviewees reported substantial physical and mental health burden as an adult after foster care.
- While interviewees described a strong connection to physical health care in adulthood, they generally avoided mental health care, a trend consistent with the quantitative findings.
- We often heard about mental health struggles including suicide attempts, substance use, and social isolation.
- We consistently heard that interviewees avoided mental health care because they did not want medication – something that they thought was forced on them in childhood – while others said that they did not want to re-live painful past traumas, that their care was insufficient, or that there is a general lack of mental health resources for adults with foster care histories.

What We Did

We interviewed 12 individuals who had completed the Foster Care Experiences Survey to learn more about their current physical and mental health needs and health care utilization. To get a mix of foster care experiences and health status, we selected people based on number of placements and self-reported health (Exhibit 2, page 5). We analyzed the interviews to identify overarching themes. Of note, this is a very small sample and may not represent the entire foster care population.

Results

Physical Health – Adulthood

Substantial Physical Health Struggles. Many of the interviewees reported that they struggle with complex physical health conditions such as obesity, cancer, physical pain, and disability. A few interviewees attributed their pain and/or disability to hard labor professions. Several participants were on or applying for social security disability benefits. Despite these significant health burdens, participants often described themselves as being "healthy."

Well-Connected to Physical Health Care. Participants reported that they felt well-connected to and had generally strong trust in their physical health care providers. Most interviewees felt that they saw their doctors when needed, that their providers genuinely cared for them, and that they were included and empowered to make decisions regarding their own health care. While a few interviewees did not think their doctors needed to know their foster care histories, most felt that their foster care experiences were relevant to their care, and they would want their providers to know that they spent time in foster care as children.

IN THEIR OWN WORDS:

"[My doctor is] amazing. I would come in with a list and we'd go over everything, and we'd sit in there for an hour."

"She [her PCP] knows everything. She knows our life story backwards and forwards."

"I have a regular PCP, and also have now the dermatologist and oncologist."

"Now as a mom, I'm so on top of everything with my kids."

"I'd rather not know if I'm going to die. I'd rather have that fantasy that everything's okay. Everything wasn't okay growing up and things were very chaotic, and I didn't have control over it."

We heard different things from interviewees about how their foster care histories may have influenced their current use of physical health care. Several participants stated that they are hyper vigilant about their own children's health and take them to see their providers regularly because their own health care was neglected at times as children. In contrast, one participant who was not well-connected to health care stated that she now avoids the doctor for fear of bad news because her childhood was so chaotic with many traumatic experiences.

Mental Health – Adulthood

Serious Mental Health Struggles, Suicide Attempts, and Substance Use. As adults, most interviewees struggle with mental health issues. Although we did not directly ask interviewees about suicide, seven of the twelve participants revealed having attempted suicide sometime in their lives. Some participants attempted suicide while in foster care and some attempted due to serious adverse responses to medications meant to treat their mental health condition(s).

Our analysis also revealed that the mention of a suicide attempt was often accompanied by having a poor experience with mental health care. Some respondents said that their suicide attempt was what finally led to them getting some, but often not enough, mental health treatment.

In addition, some of the interviewees struggled with substance use, often beginning while in foster care. Those who reported struggles with substance use also said that they went through treatment as adults and were no longer using.

Social Isolation and Feeling Alone. As adults, most participants feel isolated with no support, and few, if any, reported having friends or companions. Many participants stated that they do not have friends because they struggle with trust, and similar to how they felt as children, they are afraid of being hurt and adding negativity into their lives.

Unmet Mental Health Care Needs. Despite their extensive mental health needs, the majority of interviewees reported that they were not getting mental health care or that their care was insufficient. Some reported that they did not see the point of digging up past trauma because it just made them feel worse, and that they do not see a benefit from talking about their painful experiences. Others felt they had to justify their need for consistent treatment, and some indicated a lack of mental health care resources such as support groups for adults with foster care experience. In contrast, there were a few examples of being well-connected to mental health care, individual or family therapy, and, in these instances, it was considered a positive experience.

IN THEIR OWN WORDS:

"Now I have so many emotional problems that my doctor tried putting me on some antidepressants. All that did was make me feel more depressed and gruesomely try and commit suicide."

"I've been clean now for two years, but a little over two years ago, I tried to kill myself…It was just more like a 'I don't know what do. I'm done. I need help.'"

"I don't want to get hurt by anybody and I don't want no drama so I just stay to myself."

"It was weekly therapy when I told them that I wanted to kill myself. That was what I had to do in order to get weekly therapy. And that lasted about a month. And then it was like 'okay, well, see you in two weeks.' And now we're up to three weeks."

"I do go to therapy, but it's not enough. I feel like I could really benefit from more therapy."

"My biggest fear with seeking any kind of mental health care is that they're gonna try to put me on medication that I don't wanna be on. Because of my experience when I was in foster care, I don't wanna be medicated. I don't wanna be a zombie."

"I don't really like therapy too much because it brings up a lot of issues that really doesn't matter, that's not going to change anything but make you more depressed."

Medication Avoidance. One of the reasons many of the participants did not want mental health treatment as adults was to avoid unwanted medication. Many of the interviewees revealed bad experiences with medication in childhood and felt that it was a substitute for other treatment. Participants reported that they did not want to feel like "zombies," and one indicated that anti-depressant treatment in adulthood led to a suicide attempt.

Bottom Line: Objective 2

We saw physical and mental health disparities between people with and without foster care histories. The physical health challenges did not necessarily begin in childhood; many reported being generally health while in foster care, and despite some neglect of their health care in childhood, most reported strong connection with their physical health providers today. Importantly, we heard about mental health needs in childhood that received inadequate care, and that this had repercussions later in life as individuals struggled with mental health challenges but avoided mental health care.

Objective 3. Systems Change – Qualitative

Key Findings

Interviewees were asked about ways to improve the foster care system. Their recommendations spanned childhood through adulthood and included the following:

- A placement that feels like home
- Keep siblings together
- Explain, listen to, and empower foster kids
- More counseling/therapy in foster care
- Peer support or other stable adult outside the foster family
- A supportive network of care
- More transitional support when leaving care
- Support groups for adults with foster care experience

What We Did

During the 12 interviews of Foster Care Experiences Survey respondents, we asked about ways they would improve the foster care system. We analyzed the interviews to identify overarching themes.

Results

Recommendations from the Participants

A Placement that Feels Like Home. Participants described the ideal foster placement as one where the child feels loved, has a sense of belonging, feels at home, and truly feels like part of the family. They wanted strong communication with family members and the comfort of knowing that their needs would be met at home. Stability was important, too – ideally just having one placement and consistent people in their lives.

Keep Siblings Together. Keeping siblings together was considered essential. Interviewees thought this would help make kids feel less alone and isolated and hopefully prevent long term damage to these important familial relationships.

Explain, Listen, and Empower. It was particularly important to the interviewees that social workers, health care workers, and other adults in the child's life explain things that are happening to them and include them and consider their thoughts and feelings in decisions that impact their lives. Some also spoke about the importance of removing the stigma associated with foster children – that they are not bad kids.

IN THEIR OWN WORDS:

"The most important thing is that it's a home. That it doesn't feel like a foster home. The more you feel love and understand structure and family…the more of that gets instilled, just way better."

"A place where you feel loved. A place where you belong. A place where you know you're gonna get -- have your needs met. You're gonna have food. You're gonna have clothes. You're gonna get to go to school."

"[On not splitting up siblings] that would be one of the things that I wish they had back then. Splitting the siblings, kind of mess siblings' relationships up."

"I'd make sure the doctors listen to their patients. Instead, you're a foster kid, and they don't regard that you're still a person, like everybody else."

More Counseling/Therapy in Foster Care. Participants believed that foster children would benefit from more talk therapy to help them process their trauma and foster care experiences. Talk therapy with a consistent therapist, and not necessarily medication, would have provided them with needed support. Private individual therapy would have also allowed for a safe space to disclose any abuse or neglect they were experiencing.

Peer Support or Other Stable Adult Outside of the Foster Family. Several of the interviewees strongly recommended having a stable, supportive adult for every foster child to help them get through the difficult experience of foster care. Two participants talked about their Big Brothers and Big Sisters, and how important they were to them as children. Others desired having a more of a Peer Support Specialist as a supportive adult who had been in foster care and therefore had "walked in their shoes."

A Supportive Network of Care. Many of the interviewees did not feel heard or important while in foster care. However, one participant had a very positive experience in a group home with multiple staff because she was able to get so much attention – when one staff member was too busy, another would be available to address her needs. She had mental health care, education, hobbies, vocational training, and many supportive and nurturing adults available to her under one roof. Thus, building a supportive network of care – from social support to health care – would help ensure that foster children were cared for and that their needs were met.

More Transitional Support when Leaving Care. Interviewees suggested additional supports like vocational training to help teens who are transitioning out of foster care and are about to be on their own. Some spoke of helping foster kids build up the foundation of skills and resources, such as learning to drive and having a savings account, that are needed when they are on their own.

Support Group for Adults with Foster Care Experience. Interviewees spoke about the dearth of mental health resources after exiting foster care and suggested more resources for adults with foster care experiences. Many participants mentioned that they would appreciate a support group where they feel heard and understood by other people who have lived through similar experiences – to their knowledge no such group exists. Since many former foster youth do not have access to a support system to ask for help or advice when they need it, one participant thought a phone line for advice and crisis support would be beneficial for transitional age and adult former foster youth.

IN THEIR OWN WORDS:

"I think the counseling is very important, I think a lot of play therapy where kids can express themselves. I think kids need to be interviewed, no matter what age they are, by themselves, away from foster parents, to find out what's really going on."

"More support. More resource, life skills. More counselors. More time."

"Just more mental health services and services involving like, just transitioning, you know? Because I was at the point in my life where I was becoming an adult…I had so much chaos."

"Help getting a driver's license…a part time job…savings…so they can get independent, because they have to have the skills in order to survive once they leave foster care. If they don't have those skills, then they're going out blindly, and of course they're going to fail, because they never had that foundation to start with."

"[I could have used] somebody I could call and talk to. Maybe just to be able to call someone and -- and talk to 'em about how I'm feeling, you know…I didn't feel like I had any outside support."

"[Foster kids could use] someone who was in foster care and has walked those shoes and is able to mentor another child because they know what it's like and they have those experiences."

"[Foster kids could use] somebody who's been there. Been through the exact same experience and can help you through it."

"I think it might be good if there's like a support group for adults, you know. Just like any other kind of thing that people go through."

Summary and Conclusion

The rich study data – which included life course and foster care experience surveys, Medicaid claims, and in-depth interviews – revealed patterns of life course adversity in and out of foster care, health and health care challenges and their connection to foster care, and concrete recommendations for systems change.

Life Experiences

People who were in foster care were more likely to have adverse experiences. Most entered foster care due to physical and emotional neglect and then experienced more challenges while in the foster care system, including: not feeling loved or protected; physical, verbal, and sexual abuse (often perpetrated by a foster parent); instability due to multiple placements and switching schools; and social isolation. Most exited foster care because they aged out or ran away, and very few felt completely prepared to be on their own. In adulthood, people who were in foster care still experienced significantly more economic instability, but social support was more comparable.

Health and Health Care

While in Foster Care: Most people indicated that they generally had good physical health while in foster care, except for experiences of severe physical abuse. Some felt that their physical health needs were neglected by foster parents who would not take them to the doctor. We consistently heard about the need for mental health care while in foster care, people reported that their care was inadequate and relied too heavily on unwanted medication.

In Adulthood: People with a history of foster care had worse self-reported health and a much higher prevalence of chronic physical and mental health conditions compared to those without foster care histories. Use of primary care was comparable, but use of other physical health care was increased, such as specialty care. We heard from participants that they had good relationships with their physical health providers. In contrast, despite significant mental health struggles – including suicide attempts, substance abuse, and social isolation – we found similar use of mental health care for people with and without foster care experiences. We consistently heard that people avoided mental health care because they did not want medication and others said that they did not want to re-live painful past traumas.

Recommendations

Study participants with foster care experience made several recommendations for systems improvement, from the type of placement to ways to meet health care needs. Some of the key recommendations included adult peer support for foster children, more counseling, and support groups for adults with foster care experience.

Limitations

This was a pilot study with a relatively small foster care sample population. Further, our sample was limited to the Medicaid population, making it even more difficult to generalize the results. Several of the participants were in foster care many years ago, and so results may not completely reflect the current system. Survey responses are subject to recall bias, but research indicates accuracy in recall for traumatic events.

Conclusions

Foster care is often a traumatic experience that can have a lasting adverse impact on an individual's life course experiences and health. A pattern of experiences emerged – persistent adversity, instability, and unmet mental health needs in childhood and adulthood for Health Share of Oregon members with foster care experience. The recommendations on how to improve the system are not surprising, but they do require systems to come together, from social work to health care, to provide need care and support in childhood through adulthood.

> ***"I think being in foster care is traumatic. And I think it stays with you for the rest of your life."*** -Former Foster Youth

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