

# Using Human Centered Design to Understand the Experiences of Dually Eligible Individuals

*Lessons from Lived Experience*



**Arnold Ventures**

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# Executive Summary

Individuals who are dually eligible for both Medicare and Medicaid experience challenges with care delivery and integration because they tend to have greater health needs and lower income than other Medicare beneficiaries. With a few exceptions,<sup>1,2,3</sup> much of the research related to improving care integration for dually eligible individuals has focused on policy, plan design, and operations as a starting point rather than the lived experiences of dually eligible individuals, their caregivers, and the advocates supporting them. This report and the underlying research help to fill a significant gap in the literature by focusing on the views and experiences of dually eligible individuals and advocates, and hence is an invaluable resource for identifying strategies to improve Medicare and Medicaid program alignment.

## HOW WE CONDUCTED THIS STUDY

We used principles of Human Centered Design (HCD) to conduct an exploratory study of the ways in which integration across the Medicare and Medicaid programs, or lack thereof, affects the care experiences of dually eligible individuals. We selected the HCD approach because it provides a framework and set of tools for understanding complex, dynamic, and ill-defined challenges, such as the complex health and health-related social needs of dually eligible individuals.

Our study focused on the first two phases of the HCD process: (1) Empathize—in which we conducted empathy interviews with 48 dually eligible individuals to understand their care experiences, and six advocates who work with, or on behalf of, dually eligible individuals; and (2) Define—in which we analyzed information from the empathy interviews to articulate the challenges and gaps that dually eligible individuals encounter when seeking care.

Due to the COVID-19 pandemic restrictions, we recruited dually eligible individuals and advocates purposively through online outreach and conducted interviews via telephone and video conferencing. This resulted in a sample whose needs and experiences may differ from the broader population of dually eligible individuals. Nonetheless, this work identifies key areas on which to focus when designing or improving integrated care systems.

## WHAT WE LEARNED

Although nearly half of the dually eligible individuals in our sample are enrolled in integrated care plans, they experienced similar challenges with obtaining and coordinating necessary care and services as those who were not enrolled in integrated care plans. The extent to which individuals experienced integrated care was less related to their plan type and more related to available benefits, the efforts of their caregivers and primary care providers, the composition of the local health care market, and their ability to self-advocate.

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<sup>1</sup> Brill, R. & Gleason, B. (2021, June). Listening to dually eligible individuals: Person-centered enrollment strategies for integrated care. <https://www.healthinnovation.org/first-stop-enrollment-getting-it-right-for-medicare-medicaid-enrollees>

<sup>2</sup> Center for Consumer Engagement in Health Innovation. Consumer stories. <https://www.healthinnovation.org/work/stories>

<sup>3</sup> Summer, L., O'Malley Watts, M., Musumeci, M. (2015, August). *Dual eligible demonstrations: The beneficiary perspective*. Henry J Kaiser Family Foundation. <http://files.kff.org/attachment/issue-brief-dual-eligible-demonstrations-the-beneficiary-perspective>

In our interviews with dually eligible individuals in our study, we learned that:

- **Their concept of care is oriented toward whole-person, comprehensive care.** In their responses, individuals stressed that they desire and value care that is compassionate, collaborative, and inclusive of all aspects of life and well-being.
- **Integrated care accounts for their full range of needs and circumstances.** Dually eligible individuals perceive integrated care as less of a continuum and more of an ecosystem that encompasses their personal circumstances, including family, health, social, and logistical needs.
- **Integrated care begins with access to a network of high-quality providers.** Consistent with what is known from previous research, perceived quality of care is central to dually eligible individuals' experiences. Individuals value providers who listen to their concerns, address the root cause of their illnesses, and know how to ensure that insurance covered needed services.
- **Appropriate and timely prescribing and fulfillment of prescriptions are key components of integrated care.** Individuals in our study described providers who were unwilling to prescribe medications or suggest alternative treatment options. They recounted frustration with getting prescriptions filled and covered by insurance due to administrative processes such as prior authorizations.
- **Transportation is a frequent problem in accessing care.** Transportation mediates access to providers and pharmacies. Without it, certain services are effectively out of network for people living in rural areas and in major cities alike.
- **Telehealth mitigates certain challenges associated with receiving integrated care.** Individuals described their telehealth experiences as positive and noted that telehealth alleviated many of the challenges they experienced accessing care, such as arranging for transportation and getting timely appointments.
- **Individuals need help to understand, navigate, and coordinate their benefits to receive integrated care.** The task of discerning what care options are available and how to access them, whether benefits are integrated or not, begins when an individual is enrolling in a plan, and deciding which one will cover their providers and other necessary services like dental or vision benefits. This was also reflective of findings from previous research.
- **The most common word individuals used to describe their care experience was “frustrating.”** The main sources of frustration were situations that put the burden on them to advocate for themselves and integrate their own care.

## CONSIDERATIONS FOR POLICY AND PLAN DESIGN

Our findings identify important considerations for designing integrated plans and systems:

- **Dually eligible individuals have a range of physical and behavioral health as well as social needs.** Helping this population likely is not accomplished through plan design alone, but through hands-on approaches to identifying their needs and getting them and their families connected to care and services.

- **Individuals' needs are closely tied to their personal goals and family circumstances.** When plans and providers meet individuals where they are and understand these needs and goals, they can collaborate more effectively to improve the individual's health and well-being.
- **Provider networks play a key role in dually eligibles' experiences of integrated care.** Primary care physicians with a strong emphasis on care coordination, integrated health systems, and group practices with co-located services help individuals receive integrated care.
- **Dually eligible individuals need help identifying what benefits and services are available to them.** Proactive, knowledgeable navigators or case managers who routinely communicate with dually eligible individuals can work with the individual in a way that respects and preserves their autonomy and preferences.

# Introduction

In 2020, approximately 11.3 million Americans were enrolled in both Medicare and Medicaid, which is roughly 18% of the Medicare population.<sup>4</sup> Dually eligible individuals are a “high-cost and high-need” population for the Medicare and Medicaid programs. According to recent statistics, dually eligible individuals represent about 34% of spending under Medicare despite making up 20% of enrollees. Under Medicaid, dually eligible individuals represent about 32% of spending and 15% of enrollees.<sup>5</sup> Statistically, dually eligible individuals are more likely than other Medicare beneficiaries to experience multiple chronic conditions, functional limitations or disabilities, or a serious mental illness or substance use disorder.<sup>6</sup> In addition to their complex health needs, dually eligible individuals also experience unmet health-related social needs that often co-occur (e.g., food insecurity, social isolation).<sup>7</sup>

## EFFORTS TO INTEGRATE MEDICARE AND MEDICAID BENEFITS

The Medicare and Medicaid programs were designed to address slightly different populations and are administered differently, creating challenges for integrating the benefits and care provided under each program. The integration of benefits requires coordination between multiple payers, states, and the Centers for Medicare & Medicaid Services (CMS). In addition, the programs have different governing regulations and subregulatory guidance that drive benefit design, are often administered through third parties (such as managed care organizations) and use different operating systems for authorizations and payment. These challenges often cause fragmented care for dually eligible individuals and high costs for states, CMS, and health plans.

CMS has initiated multiple programs that aim to integrate care and benefits for the dually eligible population (Exhibit 1). These programs give states options for addressing integration issues and provide more comprehensive coverage for dually eligible individuals. However, current integrated models are not available in all states and tend to have low enrollment.

### Exhibit 1. Integrated Programs and Plan Types for Dually Eligible Individuals

Program/Plan	Description
Financial Alignment Initiative (FAI) (2011–Present)	<ul style="list-style-type: none"> <li>Aims to align the financing of Medicare/Medicaid and integrate primary, acute, behavioral health and LTSS.</li> <li>Currently operating in 11 states serving approximately 435,000 individuals.<sup>8</sup></li> </ul>

<sup>4</sup> Centers for Medicare & Medicaid Services, Medicare-Medicaid Coordination Office. (2021, April). *Medicare-Medicaid duals enrollment snapshot (quarterly release)*. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Analytics>.

<sup>5</sup> Medicaid and CHIP Payment and Access Commission. *Data Book: Beneficiaries dually eligible beneficiaries for Medicare and Medicaid*. <https://www.macpac.gov/wp-content/uploads/2020/07/Data-Book-Beneficiaries-Dually-Eligible-for-Medicare-and-Medicaid-January-2018.pdf>

<sup>6</sup> See footnote 5.

<sup>7</sup> Center for Health Care Strategies. (2020, November). *COVID-19’s effect on dually eligible populations*. <https://www.chcs.org/covid-19s-effect-on-dually-eligible-populations/>

<sup>8</sup> Medicaid and CHIP Payment and Access Commission. *Financial alignment initiative*. <https://www.macpac.gov/subtopic/financial-alignment-initiative/>



Program/Plan	Description
Program of All-Inclusive Care for the Elderly (PACE) (1994–Present)	<ul style="list-style-type: none"> <li>• Provides comprehensive adult day services in the community for individuals who qualify for nursing home care.</li> <li>• As of 2018, the program had just over 40,000 enrollees across 31 states.<sup>9</sup></li> </ul>
Dual Eligible Special Needs Plans (D-SNPs) (2006–Present)	<ul style="list-style-type: none"> <li>• A type of Medicare Advantage plan that provides combined benefits and must meet basic integration standards.</li> <li>• As of 2020, approximately 2.8 million dually eligible individuals were enrolled in D-SNPs.<sup>10</sup></li> </ul>
Primary Care Case Management (PCCM) and Limited-benefit Plans (1980s–Present)	<ul style="list-style-type: none"> <li>• In states where comprehensive managed care arrangements do not operate, states may use PCCM or limited-benefit plan programs.</li> <li>• In the PCCM model, a primary care provider is responsible for care management and coordination of an individual, paid on a fee-for-service (FFS) basis.<sup>11</sup></li> </ul>

Because of these efforts, more than one third of states have adopted Medicare-Medicaid integrated care models, known as “early-adopter” states, into their plans since January 2020.<sup>12</sup> Additionally, through the FAI and D-SNPs, there has been a significant increase in enrollment in integrated health plans. Despite these efforts, however, only 10% of qualified dually eligible individuals are enrolled in an integrated health plan.<sup>13</sup>

CMS and state policy makers have devoted considerable resources to increasing enrollment in these initiatives and improving benefit coordination and quality of care in integrated health plans. For example, to help states and health plans align benefits across payers, the CMS Medicare and Medicaid Coordination Office has created guidance documents highlighting ways to coordinate Medicare and Medicaid benefits.<sup>14</sup> Although these documents are helpful for states and health plans, the overall complexity involved in operating and coordinating benefits within integrated plans is evident. Additionally, a recent report that investigated these topics found that the factors that are most important to dually eligible individuals, and therefore, could influence enrollment in integrated plans, include having access to a wide network of providers and improving the way benefit information is disseminated to potential enrollees so that they fully understand their benefits. The

<sup>9</sup> Medicaid and CHIP Payment and Access Commission. *Program for all-inclusive care for the elderly*. <https://www.macpac.gov/subtopic/program-of-all-inclusive-care-for-the-elderly/>

<sup>10</sup> Center for Healthcare Strategies. *State efforts to integrate care for dually eligible beneficiaries: 2020 update*. <https://www.chcs.org/resource/state-efforts-to-integrate-care-for-dually-eligible-beneficiaries-2020-update/>

<sup>11</sup> Medicaid and CHIP Payment and Access Commission. *Types of managed care arrangements*. <https://www.macpac.gov/subtopic/types-of-managed-care-arrangements/>

<sup>12</sup> See footnote 10.

<sup>13</sup> Center for Healthcare Strategies. *State Efforts to Integrate Care for Dually Eligible Beneficiaries: 2020 Update*. <https://www.chcs.org/resource/state-efforts-to-integrate-care-for-dually-eligible-beneficiaries-2020-update/>

<sup>14</sup> Centers for Medicare & Medicaid Services. (2021, May). *Frequently asked questions on coordinating Medicaid benefits and dual eligible special needs plans supplemental benefits*. <https://www.cms.gov/files/document/dsnpmedicaremedicaidcoordbenefitsfaqs.pdf>

report concluded that enrollment challenges stem from limited networks that make it difficult for individuals to see their provider of choice, and barriers that prevent dually eligible individuals from understanding the benefits of joining an integrated care option.<sup>15</sup>

## HOW WE CONDUCTED THIS STUDY

We used Human Centered Design (HCD) principles to conduct an exploratory study of how integration of Medicare and Medicaid benefits, or lack thereof, affects the experiences of dually eligible individuals. By centering the needs, well-being, and experiences of this population, we identify areas where future policy- or plan-level solutions could meaningfully improve care integration.

Instead of using a set of standard research questions, we used a “How Might We” (HMW) statement to guide our study methods (e.g., our interviewee selection criteria, interview protocols, and themes we would explore). HMW statements are used in HCD to define the problem, end-user(s), and desired outcomes of potential solutions. Our initial HMW statement was “*How might we develop and implement programs that help people who are eligible for both Medicare and Medicaid seamlessly receive the care and services they need?*” Approaching this topic from the perspective of dually eligible individuals, we sought to understand:

1. What integrated care means to them;
2. How they access and navigate the health care system;
3. Which aspects of care are most important or meaningful for them; and
4. How their care experiences—both positive and negative—affect their health and their lives.

HCD typically proceeds through five phases: Empathize, Define, Ideate, Prototype, and Test. Our study focused on the first two phases of the HCD process:

*Empathize.* We conducted 1-hour empathy interviews with 48 dually eligible individuals to understand their care experiences. Empathy interviews:

- use open-ended questions to elicit stories about specific experiences that help uncover unacknowledged needs<sup>16</sup>;
- enable interviewees to discuss what they perceive as important to the topic even when it was not a topic of discussion our team identified a priori; and
- include questions about the impact of lived experiences on interviewees’ day-to-day lives and well-being.

These techniques distinguish empathy interviews from more deductive approaches to qualitative interviews, which tend to focus on soliciting opinion information on a discrete set of predetermined topic areas. Note that we did not ask dually eligible individuals specifically about their plan’s design, as our focus was on care experiences, and because laypersons often

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<sup>15</sup> Center for Consumer Engagement in Health Innovation, Community Catalyst. (2021, June). Listening to dually eligible individuals: Person-centered enrollment strategies for integrated care. <https://www.healthinnovation.org/Person-Centered-Enrollment-Strategies-for-Integrated-Care.pdf>

<sup>16</sup> Nelsestuen, K., Smith, J. (2020, October). Empathy interviews. *The Learning Professional*. <https://learningforward.org/wp-content/uploads/2020/10/tool-empathy-interviews.pdf>

have low health insurance literacy.<sup>17</sup> Rather, we focused on what makes care integrated (or fragmented) from the individual’s perspective and identified the intersections between their plan’s design and operations and their care experiences if they emerged during discussions.

We also interviewed six advocates who work with, or on behalf of, individuals who are dually eligible. We used these interviews to gather policy-level perspectives on the challenges of care integration and to inform the types of questions we asked in our interviews with dually eligible individuals.

*Define.* We systematically analyzed data from the empathy interviews to define the circumstances under which integrated care does and does not occur from the perspectives of dually eligible individuals so that plans and policy makers can design solutions that address the problems most important to dually eligible individuals. We began our analyses by identifying common and interesting findings during post-interview debriefs. Next, we used NVivo to code the interview transcripts. We used cluster and matrix coding analyses, concept mapping, consensus building, and other thematic analysis techniques to identify patterns in the coded data.

A complete description of our methods is in Appendix A. Guides for our interviews with dually eligible individuals and advocates are in Appendices B and C.

## **CHARACTERISTICS OF DUALY ELIGIBLE INDIVIDUALS IN OUR SAMPLE**

Because this is a small, exploratory study, our sample is not intended to be representative of the broader population of dually eligible individuals. Several factors influenced the composition of our sample: (1) We recruited dually eligible individuals through a study recruiting firm using a non-representative database. Individuals were contacted via email and selected purposively to achieve a mix of geographic locations, health conditions, racial and ethnic diversity, and age/sex; and (2) we conducted interviews via phone or teleconference. These factors limited the potential pool of dually eligible individuals to those who were in our recruiter’s database who have access to, and use, the internet.

These factors biased our sample toward younger, community-dwelling individuals that likely have different health conditions and personal needs than most dually eligible individuals. For example, in 2019, 38% of dually eligible individuals were younger than age 65, and about 59% were female.<sup>18,19</sup> In our sample, 90% of the individuals are younger than age 65, with 50% being 50 years old or younger, and 77% of the individuals identified as female. The experiences and challenges of individuals older than 65 or individuals living in long-term care facilities, for example, likely would have been different.

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<sup>17</sup> Edward, J., Wiggins, A., Young, M. H., & Rayens, M. K. (2019). Significant Disparities Exist in Consumer Health Insurance Literacy: Implications for Health Care Reform. *Health literacy research and practice*, 3(4), e250–e258. <https://doi.org/10.3928/24748307-20190923-01>

<sup>18</sup> CMS, Medicare-Medicaid Coordination Office. (2020, November). Data Analysis Brief: Medicare-Medicaid Dual Enrollment 2006 through 2019. <https://www.cms.gov/files/document/medicaremedicaiddualenrollmentteverenrolledtrendsdatabrief.pdf>

<sup>19</sup> Individuals younger than age 65 are eligible for Medicare if they have received Social Security Disability benefits for 24 months, or if they have end-stage renal disease (ESRD) or amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s disease). See “Who is eligible for Medicare?” <https://www.hhs.gov/answers/medicare-and-medicaid/who-is-eligible-for-medicare/index.html>

Of the 48 individuals we interviewed, 37 identified as female and 11 identified as male. The average age was 49.7 years old with most individuals being between the ages of 36 and 64 years old. Most identified as White/Caucasian (23) or African American (21). Three individuals identified as Hispanic and four identified as American Indian/Alaska Native. Of the 38 individuals who shared their plan information, just over half (20) are in an integrated plan.

Most individuals in our sample reported having complex needs, including multiple chronic conditions (45); major illness (9); one or more mental health conditions and/or cognitive impairments (33); or a functional limitation that affects their daily living (27) (for example, cleaning the house, doing dishes and laundry, going to the doctor). Exhibit 2 provides a snapshot of the demographic characteristics of our sample of dually eligible individuals.

### Exhibit 2. Characteristics of the 48 Dually Eligible Individuals in Our Study

Characteristic	Number
Male	11
Female	37
Age (average 49.7 years old, 1 unknown)	
20–35	4
36–50	20
51–64	19
65–80	5
White	23
African American	21
Hispanic	3
American Indian/Alaska Native	4
Integrated plan	20
Nonintegrated plan	18
Plan type unknown	10
Chronic conditions (not mutually exclusive)	
≥ 1 chronic condition, such as diabetes, heart disease, high blood pressure, and/or COPD	45
Major illness (ESRD, HIV, MS, cancer)	9
Mental health condition	33
Functional limitation	27

COPD = chronic obstructive pulmonary disease; ESRD = end-stage renal disease; HIV = human immunodeficiency virus; MS = multiple sclerosis

Nearly all of the individuals we interviewed (47) either lived at home or with family. One individual lived in recovery housing. Most individuals (41) were unemployed at the time of the interview. Eight individuals were both a dually eligible individual and the primary caregiver for someone else, such as a parent or child, who was either dually eligible or enrolled in Medicaid.

Several individuals shared that they have resource limitations or constraints that affect their ability to access health care services and/or purchase items and services to sustain their health and well-being. Some examples of resource limitations and constraints included:

- Inability to afford a car, which limits their ability to get to appointments in areas with poor public transportation or limited reliable, insurance-provided, transportation options;

- Inability to afford household help (and, in several cases, being denied of an insurance-provided aide);
- Limited funds to purchase household and medical support equipment, such as a walker, wheelchair, continuous positive airway pressure (CPAP) machine, and shower chair (and, in some cases, being denied benefits for insurance-covered equipment);
- Limited insurance benefits to obtain over-the-counter items such as supplements that would support health and healing;
- Limited access to reliable Wi-Fi, which has affected the ability to connect to health care providers via telehealth during the COVID-19 pandemic; and
- Issues regarding unstable, unsafe housing, which have exacerbated health conditions.

# What We Learned

The HCD principles we used to conduct this exploratory study enabled us to “learn our way forward” inductively and uncover various aspects of care integration from the perspective of dually eligible individuals. Therefore, in this section, we present our findings in a way that reflects this process.

To *promote empathy* for dually eligible individuals, we begin our findings by presenting personas and journey maps. Personas are composites that represent the typical needs, experiences, behaviors, and goals, of end users (in this case, dually eligible individuals). Journey maps illustrate the lived experiences of the individuals in our sample. Understanding these dimensions of dually eligible individuals’ experience is important for developing solutions that address their needs.

Next, we *define the problems* in integrated care from the perspective of dually eligible individuals by summarizing key themes from our interviews. These themes relate to their views on the concept of care, the intersection between their plan type and care experiences, and how their care experiences positively or negatively affect their day-to-day lives and well-being.

## **EMPATHIZE: PERSONAS AND JOURNEY MAPS OF DUALY ELIGIBLE INDIVIDUALS**

The personas we present here reflect the age range, geographic location, health conditions, and needs of individuals whom we interviewed. They also help us to see them more holistically by describing important aspects of their lives, such as their family relationships, responsibilities, fears, and personal goals. Many of the individuals we interviewed have behavioral health diagnoses and chronic health conditions; provide care for children or parents; and need help with shopping, transportation, or other daily activities. We selected characteristics and personal circumstances that were common in our sample and that best illustrate the challenges they face.

We also include a persona to represent the perspective of advocates who work on behalf of dually eligible individuals. Two of the six advocates with whom we spoke had the unique experience of being dually eligible so they understand the concerns and needs of dually eligible individuals on both a policy level and a personal level. The advocate persona we include here represents that perspective.

Following the personas, we present the journey maps that capture each step that dually eligible individuals take when seeking care, such as identifying a new provider, finding reliable transportation to their medical appointments, or getting approval from their plan for in-home care. Critically, these journey maps also show the emotional highs and lows they experience along the way, which can drive their future behaviors (for example, not filling the prescription for a needed medication or giving up on care if it is too hard to find a provider who will accept their insurance). By deconstructing the steps of their journey, we can identify touchpoints and gaps that signal opportunities for improvement in care integration, which we further define in the sections following the journey maps.

Helen exemplifies one of the younger dually eligible individuals in our sample. Although she is younger than age 65, Helen receives Medicare because her health conditions prevent her from working, and she meets the income guidelines for Medicaid. Helen is balancing her own health needs along with those of her three children, and lives in an unsafe neighborhood.



# HELEN

## Adult with Serious Mental Illness



**STORY** | Helen is a 37-year-old woman with bipolar disorder and several chronic health conditions. She is a mother to 3 children under the age of 8 and lives in a large midwestern city. She is enrolled in a D-SNP.



### GOALS

- Fixing her credit and finding a better apartment near her family.



### NEEDS

- Reliable child care so that she can attend her psychiatry appointments.
- Transportation that is timely and reliable. Helen takes a controlled substance for one of her conditions and must pick up the prescriptions in person every month.



### FEARS

- Violence near her children's school.



### CHALLENGES

- Finding a primary care physician who will accept her insurance and has appointments available. All of the doctors she has called have wait times of 6 months or more.

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Kendra represents several individuals in our sample who are both dually eligible *and* provide informal care for an aging parent who is dually eligible. Kendra’s situation highlights the important role that informal caregivers play, yet it also exposes the unstable and stressful nature of these caregiving arrangements.



# KENDRA

## Dually eligible individual caring for a dually eligible parent



**STORY** | Kendra is a 43-year-old woman with severe anxiety and several chronic health conditions. She is a mother to 2 children under the age of 18 and is the primary caregiver for her 69-year-old mother, who has dementia and several chronic health conditions. Kendra lives in a large Midwestern city. She and her mother are both enrolled in D-SNPs.



**GOALS**

- Getting healthier by quitting smoking and losing weight.



**FEARS**

- Not being able to stay on top of her or her mother’s medication needs.



**NEEDS**

- Skilled assistant or aide for her mother, so Kendra can return to work or continue her education.
- Reliable transportation for her mother when Kendra is not available to drive her to appointments. Medicaid-provided transportation is often late or a no-show, even when scheduled several days in advance.



**CHALLENGES**

- Finding specialists for her mother who accept her insurance and don’t have a long waiting list.
- Prioritizing her own health and needs in light of other caregiver demands.

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Jasmine typifies many individuals in our sample because she is heavily invested in the relationship with her primary care provider, who helps to coordinate her care and navigate benefits. This relationship is critical to her overall well-being and adherence to her care plan.



# JASMINE

Adult with multiple sclerosis and chronic conditions



**STORY** | Jasmine is a 45-year-old woman who lives in a mid-sized Southern city. She relies on the recommendations of her PCP, whom she's been seeing for over 15 years, as she navigates her care.



## GOALS

- Spend more time walking and out of her wheelchair. Her PCP recently connected her with an in-network physical therapist, and she can now spend close to 3 hours out of her chair.



## FEARS

- Her PCP retiring and having to “start over” with someone new.



## NEEDS

- A compassionate doctor who listens to her and is able to facilitate timely referrals and prescriptions as new health needs arise. This includes having a doctor who is open to adjusting treatment plans or providing a different referral if Jasmine's needs are not met.
- Being able to track all appointments and prescriptions in her doctor's online portal.
- An aide to help her with grocery shopping and cleaning.

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Vanessa represents many of the challenges that advocates discussed regarding dually eligible individuals. Among these are provider quality, open and clear communication with dually eligible individuals, and administrative barriers that are meant to control costs but prevent individuals from accessing the care they need.



# VANESSA | Advocate for beneficiaries



**STORY** | Vanessa is a peer support specialist with a nonprofit advocacy organization in California. She has been working directly with dually eligible individuals for 11 years. Vanessa had dual Medicare/Medicaid coverage for several years and is able to use her lived experience to help others.



## SPECIAL POPULATION OF INTEREST

- Works primarily with seniors with complex health needs
- Assists individuals with getting connected to care and helping them to understand the benefits for which they qualify



## CONCERNS AND RISKS

- Providers who lack cultural competency and responsiveness
- Potential for individuals to fall through the cracks if they are uncomfortable or unable to connect with their providers



## RECOMMENDATIONS TO IMPROVE CARE INTEGRATION

- Plans should use accessible language when reaching out to dually eligible individuals due to low health literacy.
- Plans should eliminate unnecessary barriers that prevent individuals from seeking care from a certain provider.



## CHALLENGES FOR BENEFICIARIES

- Many individuals qualify for certain benefits such as home care and assistive devices but do not fully understand their benefits.
- Many dually eligible individuals rely on informal networks to meet their health and social needs.

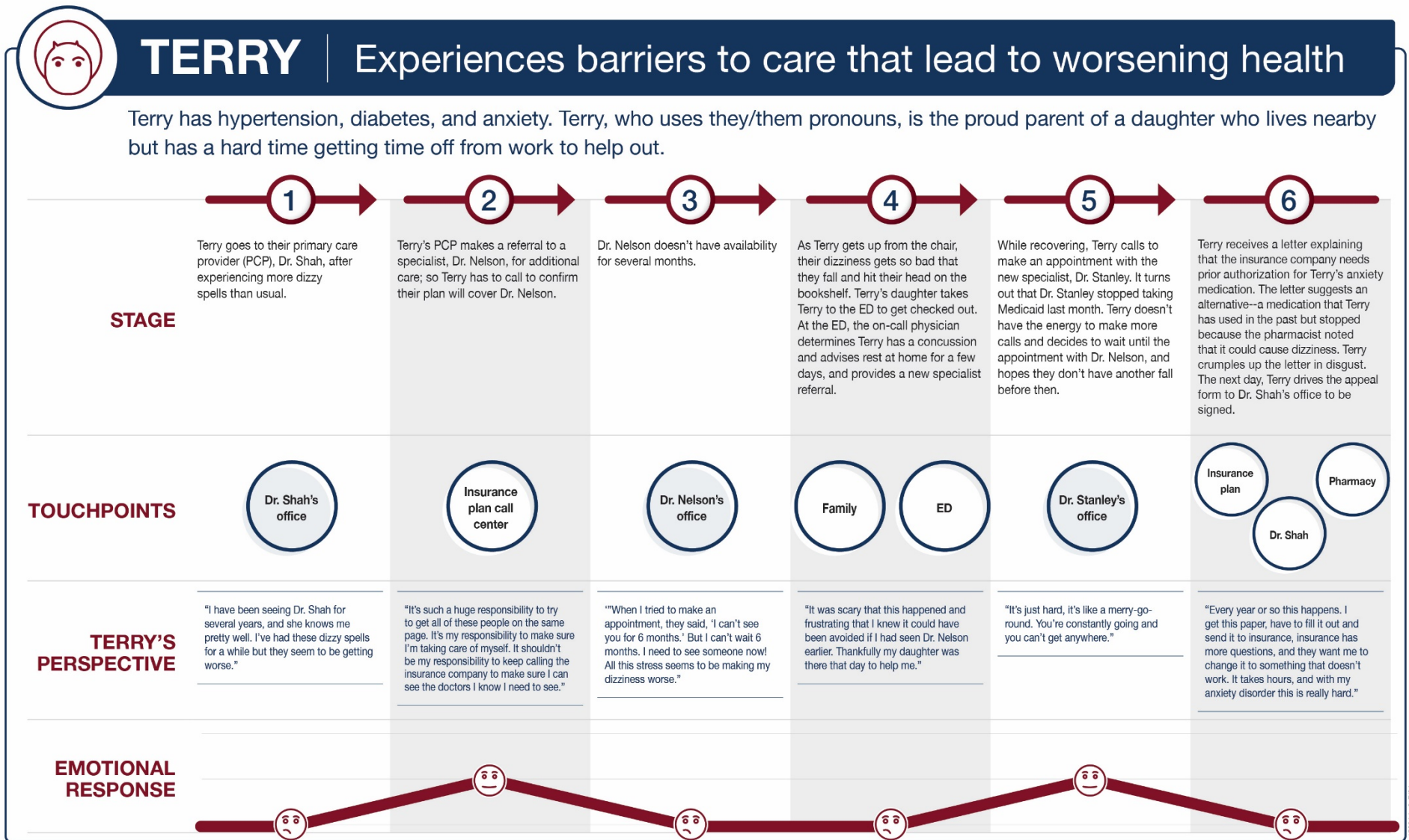


## SUCCESS STORIES/BEST PRACTICES

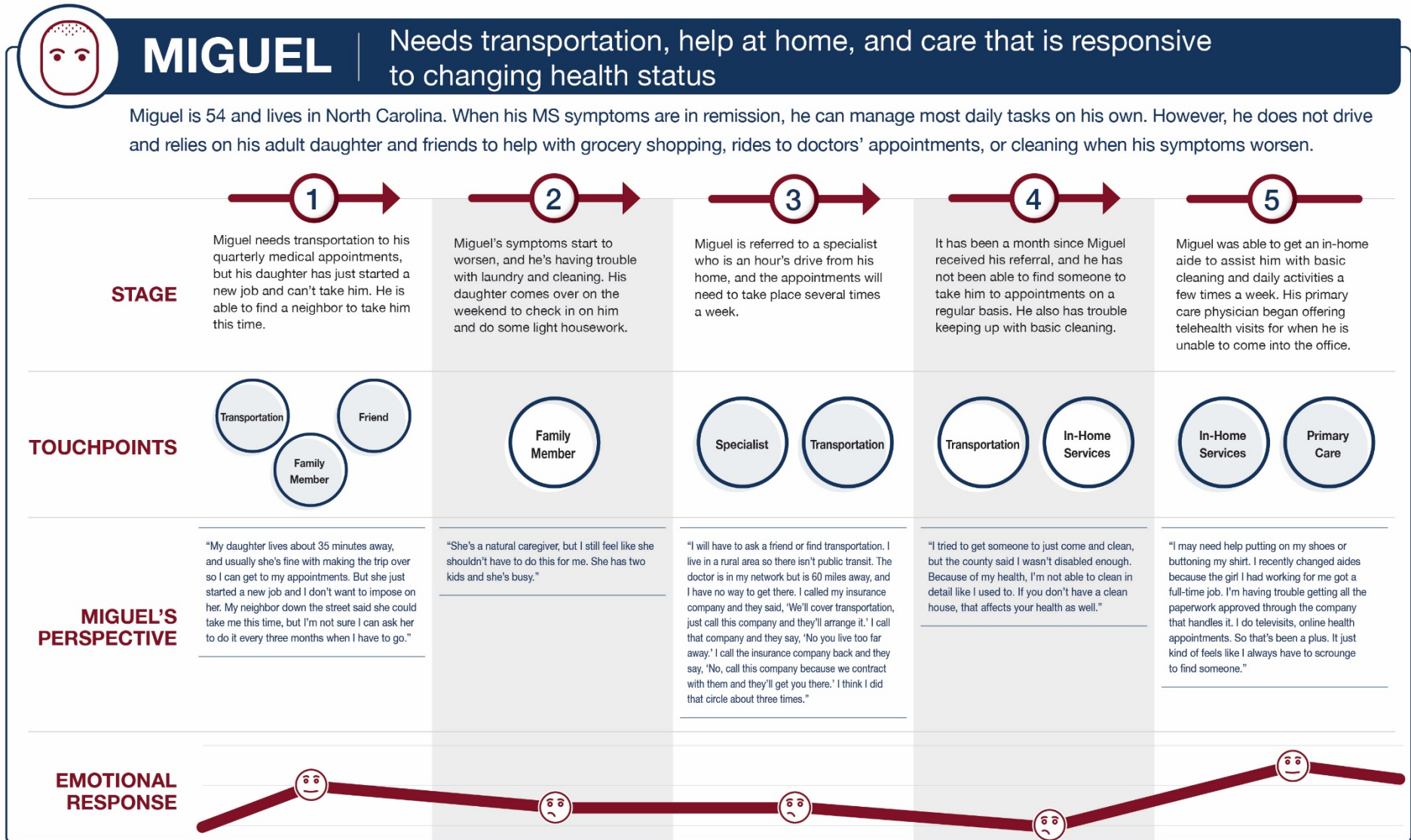
Vanessa notes that plans that work directly with providers tend to practice better care coordination; for example, a medical facility that also has an emergency care unit and allows EMTs access to a patient's medical information to provide care on the spot.

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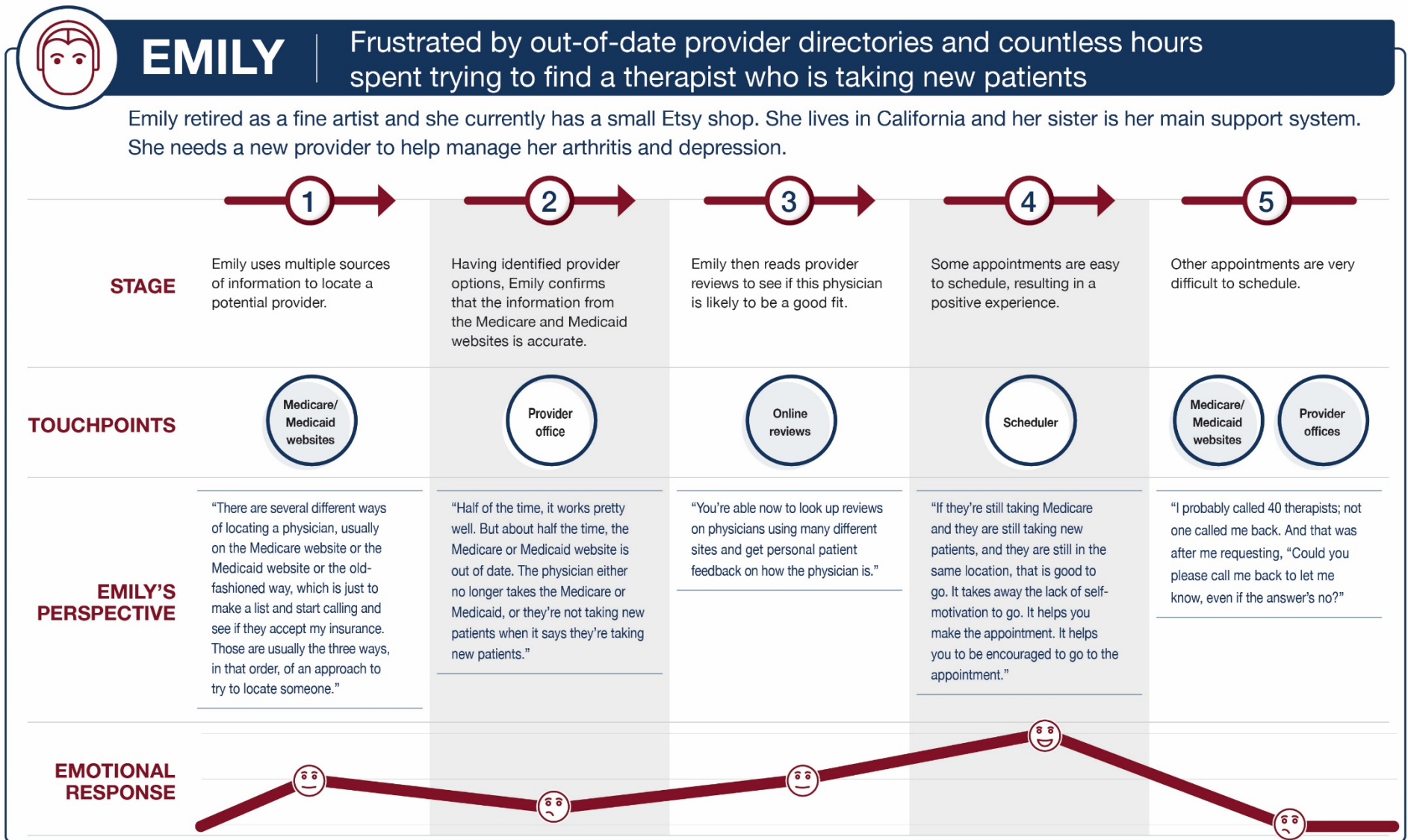
Terry's journey illustrates several barriers that were commonly cited in our interviews. Referrals to new providers—usually specialists—often require individuals to coordinate between their health plan and the new provider to ensure that the visit will be covered, which can delay needed care. Even when a provider accepts their insurance, long waiting lists are common. These types of administrative barriers and gaps in care coordination are a frequent source of frustration.



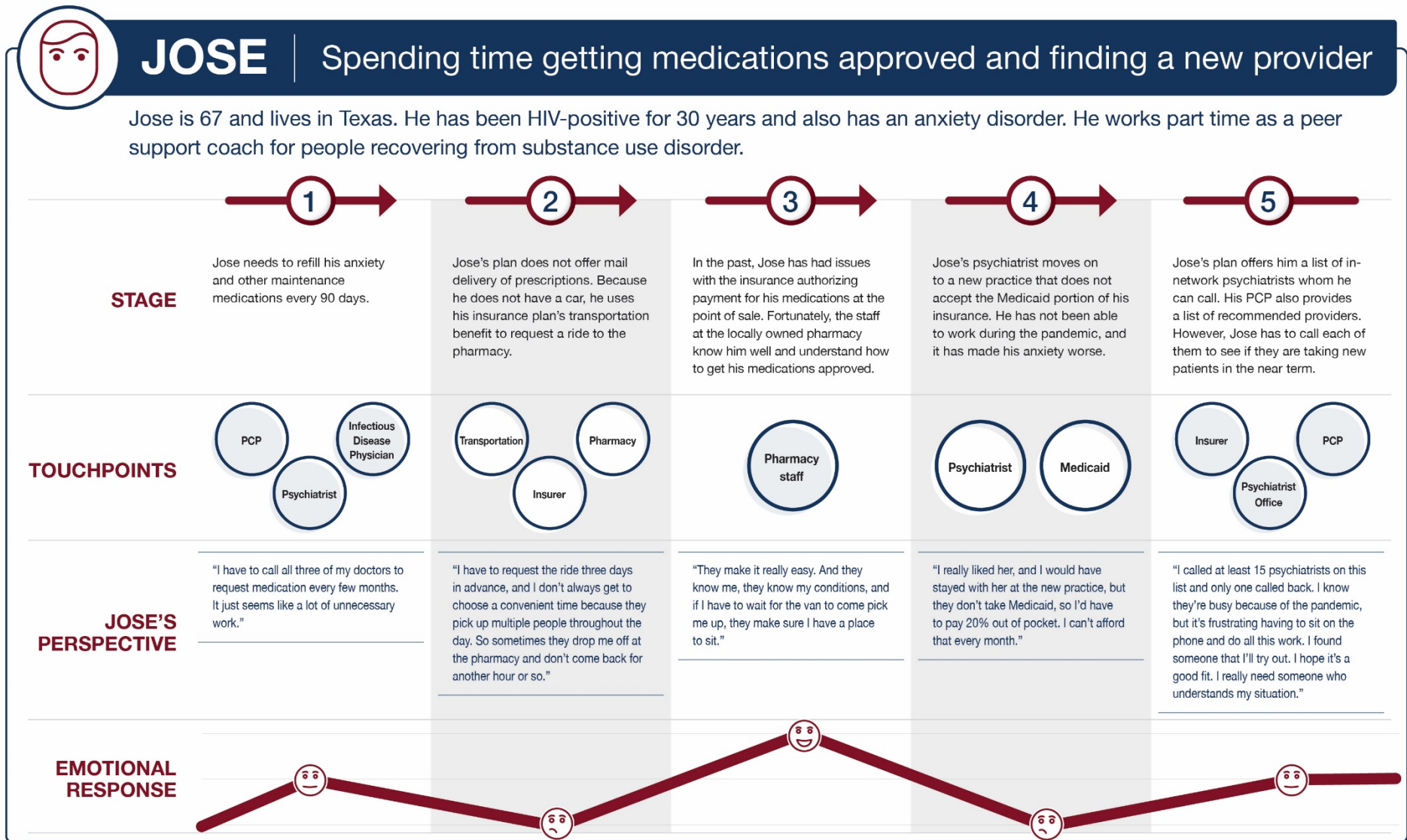
Individuals with major illnesses like Miguel often have a need for transportation to receive needed care. Although Medicaid provides transportation benefits in many states, individuals like Miguel who live in rural areas face hurdles when they attempt to access this service. In addition, help with daily activities such as cleaning and laundry are often unavailable or denied by the health plan. The struggle to access needed benefits puts further stress on individuals' overall health and quality of life.



For dually eligible individuals in our sample, the burden associated with researching and connecting to new providers was a common issue. Although many individuals wanted to do their own research to make sure the provider was a good fit, they were often frustrated by out-of-date provider directories and waiting lists. For Emily, the process of finding a new behavioral health provider was especially daunting given the demand for these providers during the COVID-19 pandemic.



Individuals in our sample often take multiple medications, some of which are costly or controlled substances. As Jose’s journey map shows, the process of requesting authorizations for these medications can be frustrating but is mitigated when there is a provider (in Jose’s case, a pharmacy) that can help navigate the approval and payment process. Jose’s journey also illustrates the impact of losing a trusted provider when they leave a plan’s network.



## DEFINE: HIGH-PRIORITY ISSUES IN CARE INTEGRATION

As the personas and journey maps show, the care experiences of dually eligible individuals in our sample are like those of other Americans navigating the health care landscape—health insurance benefits can be incomplete and confusing; high-quality care is not always readily available or accessible; and they may encounter unexpected costs. For dually eligible individuals who have limited resources, however, these gaps or barriers in the care continuum can trigger a cascade of effects.

We now turn to the Define phase of our study, in which we describe the main themes that emerged from our interviews. We begin by defining “care” and “care integration” based on the perspectives of individuals in our study, then explore issues that were identified by dually eligible individuals as the most common issues with care integration.

### ***Dually Eligible Individuals View Care as “Whole Person Care” and “Feeling Cared For”***

To get a sense of how dually eligible individuals in our sample view and value care, the first question we asked in our interviews was: *“When I say the word ‘care,’ what comes to mind for you? How do you define or think about “care?”* Although many individuals mentioned access to health care services in their responses, the most common themes related to “whole person care” and “feeling cared for by others.” Often, when individuals described health care services in their response, it was only one in a list of things that contributed to individuals feeling truly cared for. The responses below illustrate individuals’ desire for care that is compassionate, collaborative, and inclusive of all aspects of life and well-being.



Although individuals in our sample defined “care” as holistic, the care experiences that they described often did not align with their concept of care. Instead, they described experiences that were disjointed, transactional, and one dimensional. The positive experiences they described often were not the result of plan design, but local market conditions or personal factors, like living close to an integrated system or having an engaged primary care provider.

### ***Human Centered Care Integration Recognizes Dually Eligible Individuals' Full Range of Needs and Circumstances***

Policy makers and plan administrators often view care integration in terms of plan design or financing streams. However, the dually eligible individuals in our study think about and, more importantly, experience care integration differently. To them, care integration is not tied to a particular type of plan or its design. In fact, individuals rarely spoke about their plan or plan type during the interviews. Even when they were enrolled in integrated plans such as D-SNPs and MMPs, they experienced challenges using their plan to get the care they need. The dually eligible individuals in our sample perceived integrated care as consisting of:

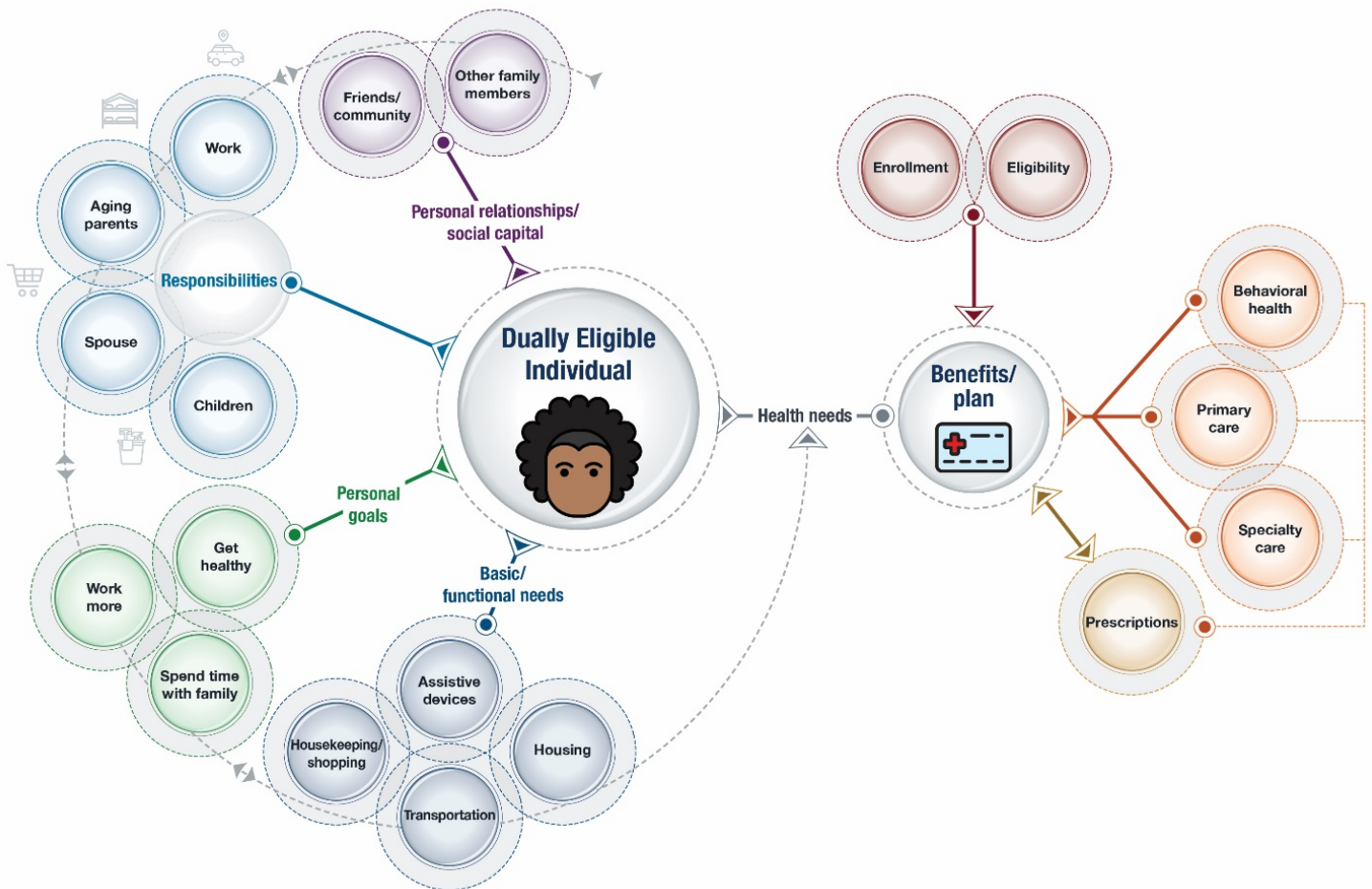
- Availability of accessible, knowledgeable, and compassionate providers who communicate with one another;
- Access to needed medications without administrative hurdles;
- Reliable transportation to get to appointments or pick up prescriptions; and
- Availability/accessibility of, and eligibility for, services and supports that address medical and nonmedical, needs (such as medical equipment, in-home aides, patient navigators, and care coordinators).

As our personas and journey maps show, these key elements of integrated care intersect with, and are influenced by, other aspects of individuals' lives. Family and friends often provide informal care, transportation, help with shopping or housework, or child care. From this perspective, care integration is less of a continuum and more of an ecosystem that embraces their personal circumstances, including family, health, social, and logistical needs.

To the extent that their care acknowledged and accounted for the factors shown in Exhibit 3, individuals in our study experienced true integration. As we describe below, however, individuals in our study faced four common barriers to care integration—accessing providers, obtaining needed prescriptions, scheduling and using transportation, and understanding their benefits. Importantly, one new option that became more widely available during the COVID-19 pandemic—telehealth—mitigated some of these challenges.



### Exhibit 3. Human Centered Care Integration



#### **Integrated Care Begins With Access to a Network of High-Quality Providers**

Perceived quality of care is central to dually eligible individuals’ experiences accessing care through their plans. When providers listened to their concerns, addressed the root cause of their illnesses, and knew how to ensure that insurance would cover needed services, individuals described their experiences as positive. Individuals also valued providers who worked together as a team to coordinate their care and enjoyed the efficiencies of receiving care from providers who were co-located or part of the same health system. Finding and maintaining relationships with in-network providers who offered these positive experiences was difficult for dually eligible individuals in our study. These challenges typically occurred when:

- they first achieved dual-eligible status;
- their providers abruptly stopped accepting their plan(s), as shown in Jose’s journey map;
- receiving referrals to specialists, as shown in Terry’s journey map.

In these circumstances, individuals spent considerable time searching for high-quality providers (via general online searches and recommendations from friends, family, and existing providers) and contacting those providers to determine whether they accepted their health plan. Hearing that providers did not accept their plans was a common source of frustration:

*“It keeps me from looking at all. It’s such a turn off. I feel turned away a lot of the time. It’s a downer, kind of. It’s not like you can just go and say, ‘I want you!’ and then they’ll accept your coverage, and your coverage will pay them. Sometimes I get this idea in my head, and I worry, that because they accept . . . Medicaid . . . that they’re sort of a lower quality doctor.”*

Individuals in our study typically did not consult their health plans when they searched for providers because they viewed the health plans’ recommendations as “random” rather than tailored to their specific needs, and because information about in-network providers was not readily available. For example, although several individuals did note that their plans mailed them booklets identifying in-network providers, others said that the lack of information about in-network doctors is a problem and suggested that plans, “send out a list and update the list every 90 days or every 6 months.” In a few instances, individuals did consult the health plan’s provider directory and found the information to be outdated.

Another challenge to accessing high-quality in-network providers is appointment availability. Many individuals described situations where they wanted an appointment sooner than one was available. At times the delays were extensive; for example, individuals were told they would need to wait several months for appointments to receive care for pressing health concerns. In some cases, they expressed serious concerns about the impact of these delays on their health:

*“I was in active addiction and needed help. The doctor did an assessment on me. But he didn’t have the certification to provide Suboxone. And he was like . . . ‘Can you hold on like 6 weeks?’ I can’t do that. But that happens a lot in addiction care. You can’t wait 6 weeks. That’s death for most people.”*

### **Appropriate and Timely Prescribing and Fulfillment of Prescriptions is a Key Component of Integrated Care**

Dually eligible individuals we interviewed discussed frustrations with various aspects of the prescription process, starting with providers who were unwilling to prescribe wanted or needed medications or unwilling to suggest an alternative treatment option if an individual requested a change for reasons such as negative side effects. Once a prescription was obtained, individuals described additional frustrations with getting the prescription filled and covered by insurance due to administrative processes, like prior authorizations.

*“I was having to call doctors; I was having to call the insurance company. It was like a miscommunication with the doctor, a miscommunication with the insurance company. The prescription company or the experts kept saying they needed more information from the doctor and it was just ridiculous, it was a nightmare.”*

In some instances, miscommunications between doctors, insurance companies, and pharmacies resulted in individuals having to make multiple calls and/or trips to the pharmacy, or medications being sent to the incorrect location. In the most extreme circumstances, these miscommunications resulted in individuals going without needed medication for weeks or months at a time. Note that in several instances, the challenges with prescriptions were because the dually eligible individuals in our study had been prescribed controlled substances.

*“...I have Adderall for the narcolepsy. Getting the insurance to agree on the dosage that the doctor set is very frustrating... They had to call the doctor's office like three or four times, and he had to fax paperwork and, which I get. Again, it's a controlled substance, but if the doctor already prescribed it, I don't understand why he has to then fill out three more forms to convince you that he meant to prescribe it that way.”*

Despite these frustrations, many individuals also had positive experiences with obtaining and filling prescribed medications. In these instances, individuals appreciated steps that the pharmacy took to make sure the medication would be covered by insurance, obtain refills, deliver medications, or just check in to see how they were feeling.

*“...sometimes they'll say, 'Well you can call your doctor, or we can call your doctor for you, and if it's not covered on the insurance plan then they'll call the doctor to see what's an alternative.... Also, the pharmacy calls to check on you and see how you're doing and how the medicine is working.’”*

### **Reliable and Flexible Transportation is a Critical Component of Care Integration**

In our interviews, transportation was a frequent problem in accessing care. Transportation mediates access to providers and pharmacies. Without it, certain services are effectively out of network for people living in rural areas and in major cities alike. Although some of the dually eligible individuals in our study owned a car, half said that they rely on either a family member or friend to take them to appointments or they use a service provided by their health plan. Health-plan-provided transportation services included bus vouchers, shared vans, and private taxi service. However, not everyone who needed transportation could get this service through their plan. Even though our interviews occurred during the COVID-19 pandemic with widespread availability of telehealth services, most individuals we interviewed still needed in-person appointments.

Those who used their plan's transportation service gave mixed reviews at best. The services often needed to be booked several days in advance, which was impossible for urgently needed care; were not reliable for getting them to their appointments on time; or required them to use a significant portion of their day to get to and from one appointment (for example, transportation was scheduled in blocks to accommodate multiple riders rather than personalized pick-up and drop-off times). The plan sometimes offered far fewer rides than the number of appointments the individual needed (for example 60 one-way rides in a year even if an individual had twice-a-week visits). Some individuals received public transportation vouchers but mentioned problems like needing quarters or the bus not coming close enough to their home.

The experiences of Kendra and Miguel highlight just a few examples of dually eligible individuals' experiences with transportation. Kendra is tasked with arranging transportation for her mother. But the transportation must be arranged in advance and still often does not show up as planned. Miguel gets help from his daughter and neighbor, but they have other responsibilities so arranging mutually available times adds to the puzzle of arranging and getting to appointments. Given the already common challenge of making timely appointments, transportation problems resulted in increased anxiety and delayed care.

*“I haven’t used it [transportation service] this year yet, but the one that I used last year, it wasn’t that good. Because sometimes they were late, and I would have to cancel the appointment and come back home. And sometimes they wouldn’t show up at all. It is [stressful] ‘cause sometimes I really have to be there. Because like last year, I had to have a surgery and they weren’t on time. I basically had to get there and couldn’t even get my ride back because that counted as a ride.”*

*“They had a taxi service you could choose among a few different ones. That was a nightmare too . . . . They were always late, and they would go to the wrong home. Just terrible, terrible, terrible.”*

*“Because I don’t fall under [my Medicare or Medicaid plan] guidelines, the next step was to get a friend to take me. I try to schedule all of my appointments on a day when he is off so he can take me. And if they’re booked up that day, then I’ll use the same day the next week.”*

### **Telehealth Mitigated Certain Challenges Associated With Receiving Integrated Care**

The COVID-19 public health emergency caused a profound increase in the use of telemedicine services. Most individuals in our study received services via telehealth in addition to in-person care. Typically, they used telehealth for routine appointments, low-acuity problem-based care, and counseling. Individuals described their telehealth experiences as positive and noted that it alleviated many of the challenges they experienced accessing care. For example, telehealth eliminated the logistical hurdles associated with arranging for transportation and physical discomfort associated with traveling to and attending appointments. In many cases, telehealth also offered appointments more quickly than possible with in-person care:

*“So since COVID . . . you can go to UrgentCare on your computer on your desk. That has been really helpful . . . . [name of insurance company] actually sent me an email and saw that I had an ear infection before. In the email they said here is your personal nurse representative person and you can call with frustrations. So I called and they said here is this app and now 24 hours a day, 7 days a week, if you need to go to the doctor, you log in and it verifies I’m me and within 5 minutes I’m with a primary care physician who is somewhere. My secondary ear infection took literally 10 minutes. Ten minutes from my chair.”*

*“Ever since COVID happened a lot of people have been doing virtual so it’s really easy to just, you know, do what I’m doing with you right now, with the doctor and not even have to go anywhere. So that’s really been really easy . . . I like it. It’s safer . . . . Appointments are quicker. It’s in the comfort of your own home, so I find it to be easier.”*

### **Individuals Need Help to Understand, Navigate, and Coordinate Their Benefits to Receive Integrated Care**

The task of discerning what care options are available, how to access them, and whether benefits are integrated or not, begins when an individual is enrolling in a plan and deciding which one will cover their care providers and necessary services like dental or vision benefits. Because dually eligible individuals have low incomes and ongoing health conditions, they may also need help organizing benefits to support housing, cleaning, meals, and utilities.

*“[When picking a plan], I was most concerned about the doctors, but I also wanted to see about the ride shares. And I also wanted to see how many [ride shares] they provide, and I wanted to see about how much they cover with my glasses. I wanted to speak about being provided meals when I have surgery. Because I had a few problems fixing my own meals because I stay alone, I wanted to see about that.”*

Several dually eligible individuals we interviewed described their experience requesting help or information from their plans. They often spent a lot of time calling the plan and waiting to get information. Even after spending considerable time on the phone, individuals in our study did not always get the support they needed, which meant that they had to spend additional time researching providers and benefits.

*“I have to do my own research. The health plan will help me, but it kind of feels like they just randomly pick ones and send it to me. It doesn’t seem like any thought or anything with my specific needs go into that, so it was really frustrating.”*

*“I have a Dual Advantage Plan and I’ve had to speak to the person who set it up for me numerous times in order to really understand how the program works. You get confusing information from various sources, so you kind of have to stay on top of it.”*

Even with Medicare and Medicaid coverage, many dually eligible individuals emphasized how much they have had to advocate to get the care they need, and how essential it was that they do so. The need for self-advocacy sometimes stemmed from positive reasons such as a desire for autonomy and making sure they found care that matched their values. But individuals also shared negative experiences that prompted their self-advocacy efforts. Informal caregivers like spouses and family members play a critical backup role in self-advocacy efforts. The journey maps of Jose and Emily highlight the amount of effort involved in tasks like finding a provider that takes Medicare and Medicaid, is accepting new patients, and has available appointments.

*“I have learned that you need to be your best advocate or find someone that can be to help you find the right doctors that you can feel comfortable with that will help you meet the medical needs that you have.”*

Navigators are a resource offered by many integrated plans, and could help dually eligible individuals track benefits, check on how they are feeling, and arrange needed care and services. In our interviews, some individuals mentioned a social worker or navigator from the plan was very helpful, but this was uncommon. It was notable that few dually eligible individuals mentioned using their plan’s navigator, even if they had one. Several said they did not hear from them, or that they were required to reach out proactively when they needed assistance. This resulted in fragmented care because, as one advocate noted, *“most people don’t even know what services they need.”* Another advocate reinforced how much work it takes to navigate multiple systems: *“The responsibility tends to lean on the dual to navigate care coordination, but it should be the care team that meets the needs of the individual.”*

Individuals who had access to a patient navigator, however, experienced more success and ease navigating their plan and benefits than individuals who did not have them. Additionally, many individuals described how their primary care provider or another trusted physician helped them arrange necessary care.



# Considerations for Policy and Plan Design

Based on feedback from our interviews, we revised our initial HMW statement to “*How might we better understand the lived experiences of dually eligible individuals to develop a more holistic, person-centered definition of care integration?*” We also offer several additional HMW statements that reflect a more holistic, person-centered definition of care integration than existing research on this topic:

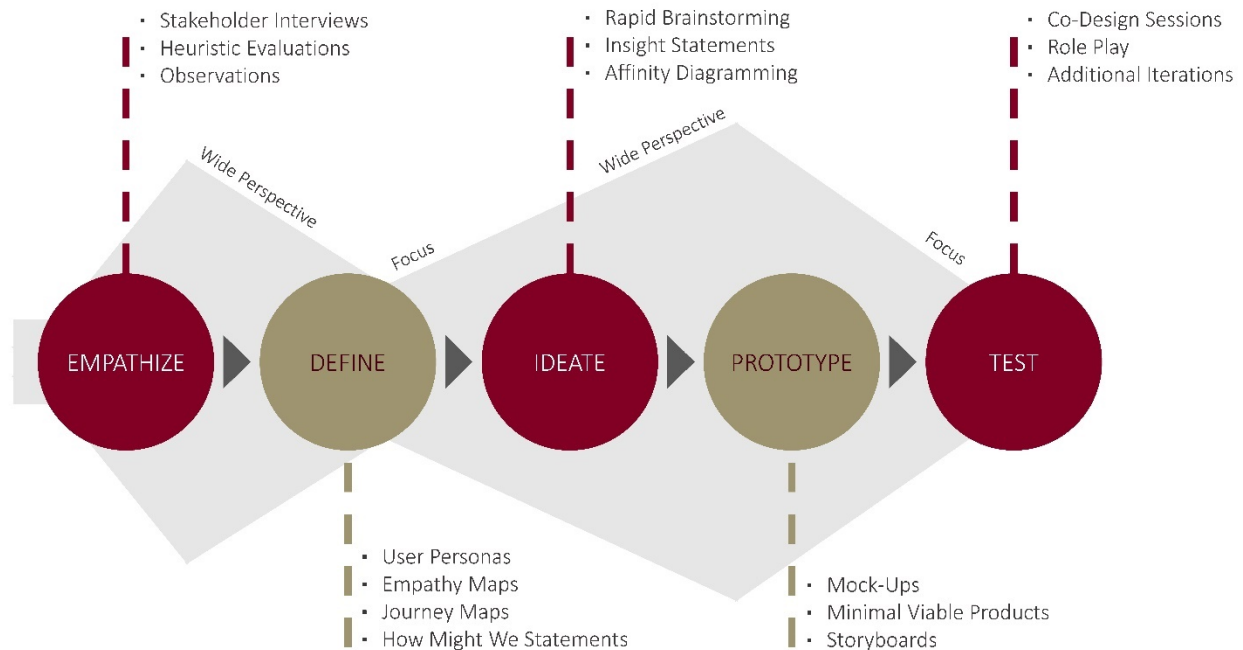
- How might we help policy makers and plan administrators reorient care integration solutions around the lived experience of dually eligible individuals?
- How might we provide dually eligible individuals with access to health care and social supports that respect their specific needs and goals?
- How might we help dually eligible individuals make seamless connections among all their health care and social service providers?
- How might we help dually eligible individuals more easily understand their available benefits?

These questions can guide plans’ and policy makers’ efforts to design care integration strategies that better address the problems of integrated care from the perspective of dually eligible individuals. We recommend that these design efforts take into consideration the following:

- **Dually eligible individuals have a range of medical and behavioral health as well as social needs.** Helping this population likely is not accomplished through plan design alone, but through hands-on approaches to identifying their needs and getting them and their families connected to care and services. We note that certain services may not be financed by Medicare or Medicaid. However, plans can play a key role in coordinating with other types of service providers and facilitating warm hand-offs.
- **Individuals’ needs are closely tied to their personal goals and family circumstances.** Dually eligible individuals often need to organize their health care and social services around care for children or aging parents, and are motivated to get or stay well so that they can fulfill caregiving responsibilities and achieve personal goals. When plans and providers meet individuals where they are and understand these needs and goals, they can collaborate better to improve the individual’s health and well-being.
- **Provider networks play a key role in dually eligible individuals’ experiences of integrated care.** Individuals who are dually eligible often have multiple providers. Primary care physicians who emphasize care coordination, integrated health systems, and group practices with co-located services can help dually eligible individuals receive integrated care if they are in-network and have appointments available.
- **Individuals who are dually eligible need help identifying what benefits and services are available to them.** Absent clear information about this, dually eligible individuals spend considerable time learning on their own through trial and error. Proactive navigators or case managers who routinely communicate with individuals can provide valuable information. A navigator or case manager should be a trusted person who is knowledgeable about the benefits and services available and works with the individual in a way that respects and preserves their autonomy and preferences.

# Appendix A—Methods and Analysis

We used principles of human centered design to explore dually eligible individuals' experience with care integration. This process enabled us to learn our way forward from the perspective of the individuals and identify issues that are most important to them. HCD typically proceeds through five phases: Empathize, Define, Ideate, Prototype, and Test.



We focused on the Empathize and Define phases that involved a series of empathy interviews with dually eligible individuals and advocates who work with, or on behalf of, dually eligible individuals and other vulnerable populations. Our goals were to:

- Develop a shared language and understanding of the issues that is grounded in the lived experience of those most affected by the challenges; and
- Make the complex and abstract problems that dually eligible individuals face tangible, and thus actionable.

## SAMPLE SELECTION

Qualitative research typically has lower sample sizes than quantitative research because the goal is not to generalize broadly, but rather to characterize aspects of a social issue (for example, experiences, feelings, interpretations) that are inaccessible via quantitative techniques. That said, research suggests that it takes approximately seven interviews before no new information is uncovered, a term that researchers refer to as saturation.<sup>20</sup> We selected a purposive sample of

<sup>20</sup> Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59–82. <https://doi.org/10.1177/1525822X05279903>



6 advocates and 48 dually eligible individuals to maximize heterogeneity and achieve saturation in responses.<sup>21</sup>

**How we selected advocates:** We conducted outreach to 25 individuals and organizations whose missions or expertise related to issues common in the dually eligible community. This included advocacy organizations that focus on older adults with low incomes, disability rights organizations, Area Agencies on Aging, organizations focused on individuals with severe mental illness, advocates for Medicaid individuals, and individuals with expertise in integrated health plans.

In the fall of 2020, we conducted six interviews with advocates from national and state-based advocacy organizations that represent vulnerable older adults, persons with disabilities and behavioral health issues, health plans, and Medicaid enrollees. Two of the advocates are, or had been, Medicaid or dually eligible individuals who brought their lived experience to their work.

**How we selected dually eligible individuals:** We engaged a professional research recruiting firm to identify dually eligible individuals nationwide. The firm conducted two rounds of email outreach in December of 2020 and January of 2021 to its database of approximately 1 million individuals using a screening tool that we developed. The screening tool asked individuals to identify their state of residence, whether they received both Medicare and Medicaid benefits (or whether they were a caregiver for someone with these benefits), their health conditions, their age, race/ethnicity, gender, and whether they receive Social Security Disability benefits.

We received 1,627 responses to the outreach email; of those responses, 70 met the screening criteria, and 48 responded to the request for an interview.

Between January 2021 and March 2021, we interviewed 48 dually eligible individuals from 16 states—Alabama, Arizona, California, Colorado, Florida, Georgia, Indiana, Michigan, Minnesota, Missouri, Nebraska, New York, North Carolina, Ohio, South Carolina, and Texas.

The states represented vary in the degree of integrated care plans available to dually eligible individuals. Seven of the states in our sample offer Fully Integrated or Highly Integrated D-SNPs, while the remaining nine states offer D-SNPs.

## HOW WE CONDUCTED INTERVIEWS

We developed separate interview guides for individuals and advocates to elicit their experiences, thoughts, and recommendations related to the provision of care and care integration.<sup>22</sup> (See Appendices B and C) We pilot-tested the interview guide for dually eligible individuals with three individuals who served as proxies and updated the guide and our protocols based on the results of the pilot interviews. Our research design and interview guides were reviewed by an institutional review board.

As part of the HCD process, we conducted interviews in an inductive fashion. That is, we used the structured interview protocol to explore issues related to individuals' experiences of care (or advocates' experiences and policy recommendations), but we allowed them to guide the

<sup>21</sup> Ilker Etikan, Sulaiman Abubakar Musa, Rukayya Sunusi Alkassim. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), pp. 1-4. doi: 10.11648/j.ajtas.20160501.11. <http://www.sciencepublishinggroup.com/journal/paperinfo?journalid=146&doi=10.11648/j.ajtas.20160501.11>

<sup>22</sup> See Appendices A and B.

conversation and focus on areas that are important to them. This approach contrasts with a deductive approach, which uses a structured question/answer format and is often grounded in predetermined assumptions about their experience.

We probed or asked follow-up questions to delve into individuals' or advocates' pain points or positive experiences. This enabled us to uncover adjacent problems to inform care integration and uncover other aspects of care that are worthy of future research. All interviews lasted approximately one hour and were recorded and transcribed.

## **ANALYSIS**

We analyzed interview data using a stepwise process:

First, we conducted periodic debriefings to identify early patterns in the data, refine interview questions, identify new areas to explore, and identify a start list of codes. We used NVivo software to systematically code the data from transcripts and determine which code(s) should be kept, combined, revised.

Next, we conducted coding checks for interrater reliability to assess consistency between coders. For 15% of our interviews, two coders independently coded the same interviews, and two senior researchers reviewed the agreement between the codes used.

We also conducted cluster analyses, matrix queries, word frequencies, and node maps to identify key themes and the relationships between concepts. We also used these analyses to identify themes related to individuals' or advocates' attributes. For example, we explored whether certain themes were more prevalent among individuals who were enrolled in a D-SNP or among those who had behavioral health issues.

We developed personas (archetypes that identify characteristics that are meaningfully relevant to the problem to be solved) and journey maps (visual displays of how the personas experience the problem to be solved) to summarize the findings of these exploratory analyses. These are based on real experiences, but names have been altered.

# Appendix B—Interview/Discussion Guide for Dually Eligible Individuals

## INTRODUCTION AND CONSENT

Hello, my name is \_\_\_\_\_. I work for IMPAQ International, an independent research & evaluation firm that has been hired by Arnold Ventures to learn about the experiences of people who have health insurance from both Medicare and [enter name of Medicaid program in state]. We'd like to ask you some questions about your health care and daily routine—who helps you get around, go to the store or do the things you like to do. We'd also like to talk about the times you might have trouble getting something you need.

You are not required to do this interview. You can skip any questions you do not want to answer and stop the interview at any time. Your answers will not affect any benefits that you currently get through [enter name of Medicaid program in state], Medicare, or any other federal or state programs. Your answers will be kept confidential and stored separately from your contact information, and we will not share your contact information or interview answers with anyone outside the study team. None of our reports will include any information that identifies you. Your answers will be combined with the answers of about 50 other individuals.

*This interview will take about 45 to 60 minutes. As a “thank you” for participating, we will send you a \$75 gift card.*

- *Do you agree to participate in the interview?*
  - *Do we have your permission to record this conversation for note-taking purposes?*
  - *Do you have any questions for me before we get started?*
1. When I say the word “care”, what comes to mind for you? How do you define or think about “care?”

[If we use the photovoice method: We asked you to take a picture of an important aspect of the care or support you receive that helps you meet your health goals. Can you tell me what is happening in this picture and what made you take a picture of this?]

2. How often do you go to the doctor?
  - a. How did you figure out what doctor you should go to?
  - b. How do you usually get to your doctor's office?

[If they mention transportation services, ask how they learned about that service, who arranges it (them or the doctor's office) and if they have to pay for it.]

- i. Do you usually have to pay anything when you are at the doctor's office?
- ii. What is the hardest part about going to the doctor?
- iii. What is the easiest part about going to the doctor?

3. When you need to have a prescription filled or get a medical device your doctor recommended, what do you do? *(Tailor questions as needed for individuals who cannot answer.)*
  - a. Do you usually have to pay for your prescriptions or medical device?
  - b. What is the hardest part about getting a prescription filled or getting a medical device your doctor recommended?
  - c. What is the easiest part about getting a prescription filled or getting a medical device your doctor recommended?
4. Outside of your friends/family/neighbors, does anyone help you do things that are hard to do because of your health? For example, personal aides, meal delivery, take you to medical appointments, etc.?
  - a. Who helps you?
  - b. How do they help you?
  - c. How did you figure out who could help you with that? How did you figure out who could help you with that?  
To get that help, do they call you, you call them, or someone else calls them for you?
  - d. Do you have to pay for that help?
5. Who do you usually call when you need help with finding a doctor or someone to help you do things that are hard to do because of your health? *(This question helps identify their entry point to care and understanding of how to navigate it.)*
  - a. Do they usually do a good or bad job at helping you? Tell me what makes them [good/bad]?

### **DUALLY ELIGIBLE INDIVIDUAL CARE EXPERIENCES**

6. Can you think of a time when you needed care/help and had a hard time getting it? Tell us about that experience.
  - a. How did this negative experience affect you?
7. Can you think of a time when you needed care/help and you had an easy time getting it? Tell us about that experience.
  - a. How did this positive experience affect you?
8. Please look at this list of words and choose 5 that describe your overall experience getting care and help with things that are hard to do because of your health.

<input type="checkbox"/> Accessible	<input type="checkbox"/> Easy	<input type="checkbox"/> Helpful	<input type="checkbox"/> Organized	<input type="checkbox"/> Slow
<input type="checkbox"/> Caring	<input type="checkbox"/> Empowering	<input type="checkbox"/> Hard	<input type="checkbox"/> Overwhelming	<input type="checkbox"/> Stressful
<input type="checkbox"/> Complicated	<input type="checkbox"/> Fast	<input type="checkbox"/> Inconsistent	<input type="checkbox"/> Personal	<input type="checkbox"/> Trustworthy
<input type="checkbox"/> Comprehensive	<input type="checkbox"/> Flexible	<input type="checkbox"/> Intimidating	<input type="checkbox"/> Reliable	<input type="checkbox"/> Unpredictable
<input type="checkbox"/> Confusing	<input type="checkbox"/> Frustrating	<input type="checkbox"/> Enjoyable	<input type="checkbox"/> Rigid	<input type="checkbox"/> Valuable

9. What made you choose these words?
10. Generally speaking, what are your most important goals right now?
11. What kind of care or support would help you achieve those goals?
12. Is there anything else you would like to tell me about your experiences getting the care and support you need to meet your goals?

**Thank you very much for your time today.**

# Appendix C—Interview/Discussion Guide for Advocates

## INTRODUCTION AND CONSENT

Hello, my name is \_\_\_\_\_. I work for IMPAQ International, an independent research & evaluation firm that has been hired by Arnold Ventures to explore individual experiences with coordinated care offered under the Medicare and Medicaid programs. As we discussed in our initial outreach to you, we are interviewing individuals who advocate for dually eligible individuals in order to better understand your experience working with, and on behalf of, this population. We'd like to ask you some questions about the nature of your work and the main challenges that individuals face in obtaining coordinated care that meets their needs. The study was approved by an independent Institutional Review Board.

We want to assure you that your participation in this interview is entirely voluntary. You only need to respond to those questions you wish to answer, and you may stop the interview at any time. All interview responses will be kept confidential and stored separately from your contact information, and we will not share your contact information or interview responses with anyone outside the study team. This is also a good time to emphasize that none of our reports will include any information that identifies you.<sup>23</sup> Your responses today will be combined with the responses collected from other advocates.

*We estimate that the interview will take about one hour.*

- *Do you agree to participate in the interview?*
- *Do we have your permission to record this conversation for note-taking purposes?*
- *Do you have any questions for me before we get started?*

## ADVOCACY BACKGROUND

First, we want to get a sense of your background and experience working as an advocate.

1. How long have you been working as an advocate for dually eligible individuals?
2. Can you describe some of the work that you do on behalf of dually eligible individuals?
3. Do you work with particular populations, such as children, individuals with disabilities, etc.?

## INDIVIDUAL CARE REQUIREMENTS

Now, I'd like to turn to a discussion of the care requirements of individuals that you serve, and any associated challenges and facilitators of that care, based on your observations and interactions with them.

4. What do you see as some of the day-to-day barriers and challenges that this population faces? (probe for examples)

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<sup>23</sup> We obtained advocates' permission to use their names in the acknowledgments section.

- a. What do you see as some of the main drivers of these challenges?
5. What are the various aspects of care that are important for individuals' health and well-being, and that must be part of what Medicaid and Medicare offer?

### **INDIVIDUAL EXPERIENCES WITH INTEGRATED CARE**

6. Can you recall a time when you were advocating for a dually eligible individual/individuals and you were unable to get the resolution that they needed? Tell me about that situation, and the degree to which integrated care (or lack thereof) played a role.
7. Can you think of a success story related to a dually eligible individual/individuals receiving the care and services they need? Tell me about that situation, and the degree to which integrated care (or lack thereof) played a role.
8. Under what circumstances, if any, do you think dually eligible individuals receive more integrated care? For example, does it depend on what kind of plan they are in? What kind of care they need?
9. What do you see as the major system or organizational-level challenges for this population, as it relates to accessing and receiving care?

### **POLICY AND PROGRAMMATIC SOLUTIONS**

Now, I'd like to ask you just a few questions on any suggestions you may have for improvements that can be made towards better care delivery.

10. What suggestions do you have for ways to better integrate care for dually eligible individuals? Examples of successful practices from other states or other programs?
11. If you had a few minutes to talk with state leaders in the Medicare and Medicaid programs about improved care coordination for dual eligible individuals, what are the main points you would want to make?

### **RECRUITING**

We are planning to conduct interviews with individuals to hear about their experiences first hand.

12. Would you be open to helping us identify and contact individuals to participate in the interview?
13. Do you have any suggestions for service organizations or health plans who might be open to helping us identify and contact individuals to interview?

### **CLOSING**

14. And finally, is there anything else related to the topic of coordinated care for dual eligibles that you would like to make before we end this interview?

Those were all of the questions I had for you today, and we certainly want to be mindful of your time. If you have any questions or comments in the future, please feel free to contact us. Our project director's phone number and email address were sent in the informational email about the interview. Would you like me to repeat it for you? **Thank you for your time today. Goodbye.**