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Integrated Appeals & Grievances Demonstration in New York:

Beneficiary Experience Research

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Overview

This is a summary of research results about how beneficiaries dually eligible for full Medicare and Medicaid benefits[1] experienced the Integrated Appeals and Grievances (A&G) demonstration in New York. The state and CMS launched this demonstration on January 1, 2020 to test the continued implementation of the integrated process. That process was first developed in New York's Fully Integrated Duals Advantage (FIDA) demonstration under the Medicare-Medicaid Financial Alignment Initiative, which ended on December 31, 2019. The Integrated A&G demonstration tests the integration of the appeals and grievances process for beneficiaries enrolled in Fully Integrated Dual Eligible Special Needs Plans (FIDE SNPs). Under the demonstration, beneficiaries use one process for appealing Medicare and Medicaid coverage decisions that the plan makes, rather than navigating two separate health insurance systems.

There are four levels in the appeals process as depicted in Exhibit 1. It starts with an enrollee appeal directly to the plan regarding a coverage decision (Level 1). If the plan upholds its decision – that is, it does not reverse the reduction or denial of benefits – an integrated appeal is automatically forwarded to hearing officers in the New York Integrated Administrative Hearing Officer (IAHO), which determines whether to uphold or reverse the plan's decision (Level 2). Beneficiaries who disagree with the IAHO decision can appeal to the Medicare Appeals Council (Level 3) and finally to Federal District Court (Level 4).

In preparation for Level 2 appeals, the health plan sends the beneficiary and the IAHO hearing officer a packet of in-depth information called "the evidence packet". The evidence packet includes medical records, information that the health plan used to make their initial adverse determination decision, and copies of the most recent one or two Uniform Assessment Tool (UAT) results.[2] The hearing officer reviews the evidence and may reference the evidence packet during the hearing. IAHO hearings are generally conducted in English, though translators are generally available for beneficiaries requesting this service. Health plans track beneficiary's preferred language and offer various types of support, including answering beneficiary's questions, filing appeal requests, and providing written materials in languages other than English. Previous research suggests that navigating the Medicare Advantage appeals process is inherently challenging, and individuals navigating the appeals process experienced difficulty understanding technical language in written materials, as well as stress and declines in health conditions.[3]

The results of this research are based on our interviews with dually eligible beneficiaries who are enrolled in the state's FIDE SNPs, known as Medicaid Advantage Plus (MAP) plans, and have filed at least one appeal during 2021 with their MAP plan. This research was conducted through a Centers for Medicare & Medicaid Services contract for beneficiary experience research. None of these findings are indications of compliance (or lack thereof) with the three-way-contract that governs the demonstration.

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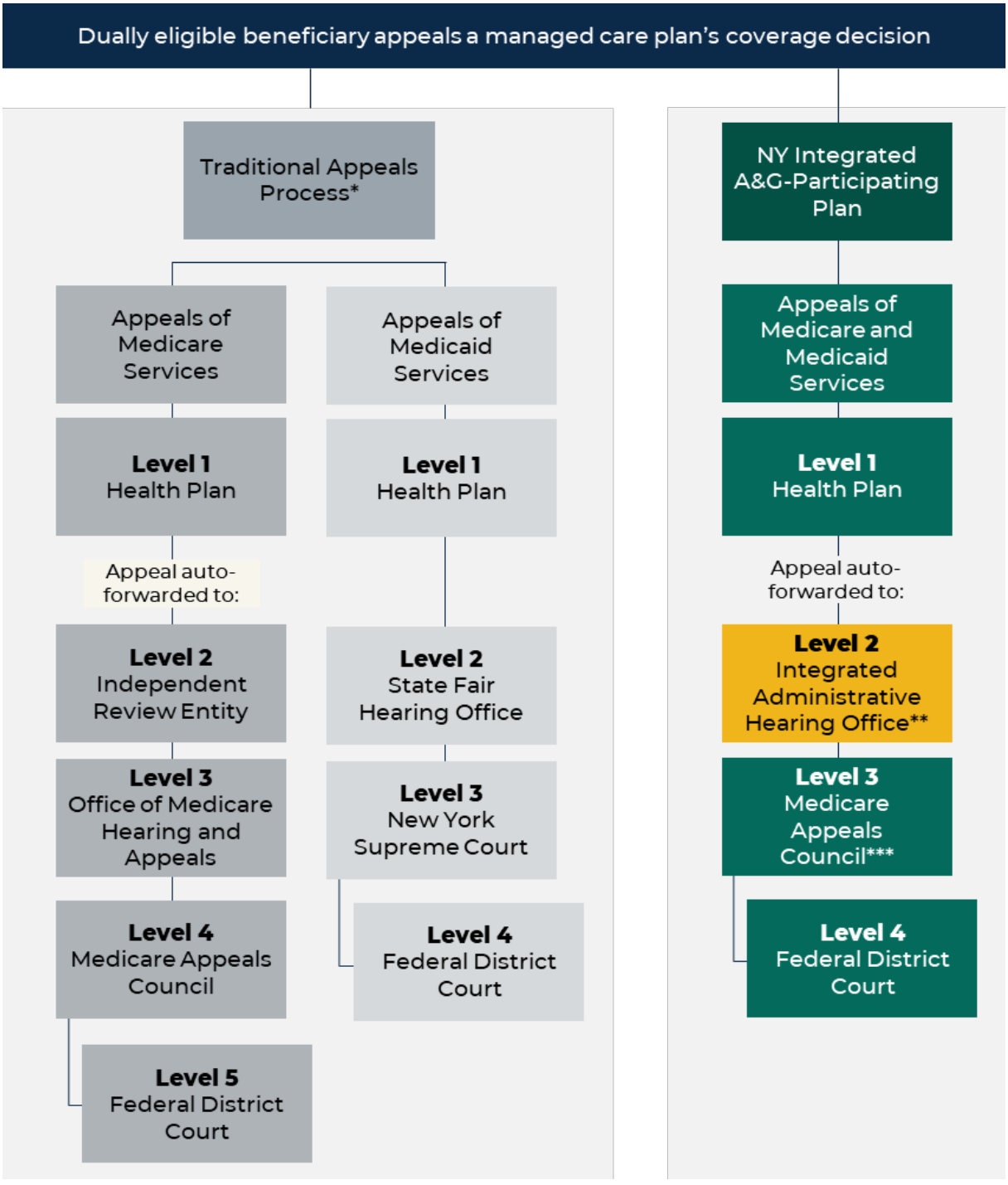
[1] Only Full Benefit Dually Eligible Individuals are eligible for MAP. Individuals who are only eligible as a Qualified Medicare Beneficiary (QMB), Specified Low Income Medicare Beneficiary (SLIMB) or a Qualified Individual-1 (QI-1) and are not otherwise eligible for Medical Assistance, are not eligible for MAP. NY Medicaid Advantage Plus (MAP) Model Contract. Section 5.2(b). Available at https://www.health.ny.gov/health_care/medicaid/redesign/mrt90/docs/2022-2026-map_model_contract.pdf.

[2] New York uses the Uniform Assessment Tool (UAT) to collect consistent information to determine a person's ability to remain at home and to identify the necessary supportive services required to provide a safe home environment. More information about the UAT is available at https://www.health.ny.gov/health_care/medicaid/redesign/mrt90/2009-04-08_fox_report.htm.

[3] U.S. Department of Health and Human Services, Office of Inspector General. 2018. "Medicare Advantage Appeal Outcomes and Audit Findings Raise Concerns about Service and Payment Denials." Office of Inspector General, 2018. Available at https://oig.hhs.gov/oei/reports/oei-09-16-00410.pdf. Accessed June 25, 2022.

Exhibit 1. Integrated appeals and grievances process in New York Medicaid Advantage Plus plans



* Could include Medicare Advantage, Medicaid mainstream managed care, and Medicaid managed long-term care plans.
** The New York Integrated Hearing Office at the New York Office of Temporary and Disability Assistance for the demonstration is located in New York City.
*** The Medicare Appeals Council is a component of the U.S. Department of Health and Human Services Departmental Appeals Board.

Methods

We conducted semi-structured telephone interviews with beneficiaries who were dually eligible for full Medicare and Medicaid benefits from March to May 2022. We identified and recruited beneficiaries from four of the eleven total MAP plans in New York.[4] We recruited research participants from these four MAP plans because they enrolled the largest number of beneficiaries and had the greatest number of appeals decided by the IAHO between Quarter 1 and Quarter 3 of 2021 (the study planning period). Beneficiaries were eligible to take part in the study if they enrolled in one of these four MAP plans and had filed at least one appeal of their health plan's denial of coverage of a service or medical item between January 1 and December 31, 2021. We oversampled individuals who spoke Spanish because they represent over 50 percent of beneficiaries with an integrated Level 2 appeal[5] and to understand whether this group had distinct experiences in navigating the process compared to those who speak English. In all, we conducted 22 beneficiary interviews; five of the 22 interviews were with a family member or other authorized representative speaking on the beneficiary's behalf. We also interviewed five professionals from organizations that assist beneficiaries in navigating the integrated appeals process.

The study team conducted a thematic analysis of the interview data and used the themes that emerged from the analysis to develop user personas, which depict beneficiaries whose characteristics and experiences represent those of the larger group of beneficiaries in these plans. User personas are a useful technique to understand beneficiaries' experience because they succinctly communicate information about beneficiary reported needs, concerns, or expectations. Based on beneficiary experiences, we categorized respondents into two groups and developed fictitious user personas based on prominent themes that emerged from the data. The first persona represents beneficiaries who received support navigating the appeals process from their health plan and/or informal caregivers ("high-touch") and is shown in Exhibit 2. The second persona represents beneficiaries who received little to no support navigating the appeals process from their health plan or informal caregivers ("low-touch") and is shown in Exhibit 3. We also developed a journey map as a graphic depiction of beneficiary experiences, reported challenges, and actions taken by beneficiaries, health plans, and the IAHO during the integrated appeals process based on the experiences of interviewees (Exhibit 4). Journey mapping is useful for identifying challenges common to interviewees and understanding how individuals navigate each stage of the integrated appeals process.

[4] The number of plans participating in the demonstration grew from eight in 2020 to 13 as of the writing of this report.

[5] This information came from an unpublished report on MAP integrated appeals from New York's Office of Temporary and Disability Assistance. Shared with Mathematica on August 5, 2022.

Key Findings

Beneficiary support needs while navigating the integrated appeals process

- Nearly half of beneficiary interviewees received support from a family caregiver during the appeals process. Family caregivers provided various types of support, including help navigating the appeal process, filing appeal requests on the beneficiary's behalf, reviewing the evidence packet with the beneficiary, participating in the IAHO hearing, and increasing the beneficiary's understanding of the integrated appeal process.

"I may be a little slow in picking up some things [during the hearing]… After we left [the hearing], my son explained to me…so I understood everything.

-Spanish-speaking beneficiary

- All interviewees who did not have informal support reported communication-related challenges, such as low vision or inability to read, and expressed limited understanding of the appeals process.
- Most interviewees who spoke Spanish reported more obstacles that likely affected their understanding of the appeals process. For example, person-specific information (such as reasons for denial decisions and sections of the evidence packet), are not routinely translated into a beneficiary's preferred language.

"I get lost. They talk these lingo and words. I don't know. Then, you give up because you don't know how to prove yourself."

-English-speaking beneficiary

Role of professionals in helping beneficiaries navigate the integrated appeals process

- Beneficiaries connect with professionals in many ways, including through community-based organizations that make referrals, intake hotlines operated by legal aid organizations, or the long-term care ombudsman program in New York. Professionals reported providing a range of free support to beneficiaries, which varies depending on the beneficiary's place in the appeals process. These services could include providing direct legal counsel to beneficiaries during the IAHO hearing or helping the beneficiary prepare for the hearing by reviewing plan notices and the evidence packet or answering questions about the process.

"I can usually get a lot added to the [evidence packet] to make my case. For a beneficiary representing themselves, it is going to look like gibberish.

-Professional interviewee

- Professionals described bringing expertise in navigating the appeals process that may be advantageous to the beneficiaries with whom they work. For example, professionals have experience reviewing the assessment forms that are included in the evidence packet and using that information to support the beneficiary's case during the IAHO hearing.

Experience with the integrated appeals process

- About a third of beneficiaries reported that the auto-forwarding of their second level appeal to IAHO eliminated the need for them to push their appeal forward. These beneficiaries preferred the automatic forwarding process because they believed it protected them from unintentionally skipping a step in the integrated appeals process. Another third of interviewees were not aware that their case was auto-forwarded and learned about it when the study team asked them about it. Professionals reported that auto-forwarding is an important protection for beneficiaries whose appeal is denied by the plan.

> *"I don't know anything I'm doing, so I rather somebody that knows what they're doing to do it for me. I felt more comfortable than me messing it up."*
>
> -English-speaking beneficiary

- Beneficiaries who requested a translator for their IAHO hearing reported that they appreciated having the service available.
- About a third of interviewees reported waiting from a few weeks to a few months between the initial denial of their appeal and their IAHO hearing, and others could not provide an estimated time frame. Half of interviewees reported having unmet health and support needs during the appeal period that affected their health or quality of life.[6] Some experienced mental stress from managing their unmet care needs; being reliant on others for support; and other stressors, such as social isolation. About half of beneficiary interviewees reported insufficient opportunities to discuss their case during their IAHO hearing. These interviewees described feeling "unheard" or "not listened to" during their hearing as their questions were not answered or because their confusion about their case was not fully resolved.

> *"Because in the meantime [in the waiting period], I'm sick. I'm frustrated with this. I spoke to my therapist about it, too. Because, I got really depressed about it."*
>
> -English-speaking beneficiary

Experience with communications about the integrated appeals process

- More than half of beneficiary interviewees received some support from their health plan during the appeals process. Health plans helped by answering beneficiaries' questions, filing the initial appeal request on their behalf, guiding them through the Level 2 integrated appeal process, acting on requests to receive written materials in a language other than English, and calling them to inform them of the hearing date and time.

> *"Having a case manager [from the health plan] to be on my team and get things done. It was helpful to have someone who knows my history and can help break down the insurance terminology."*
>
> -English-speaking beneficiary

[6] Another quarter of interviewees reported that their health conditions stayed the same during the appeal period, largely because these individuals continued to receive the item or personal care services until their appeal was resolved or because they had a caregiver who provided support.

- Health plans record the beneficiary's preferred language in their administrative data, but materials are not always provided in that language.
- Only about half of beneficiaries interviewed recalled receiving an evidence packet from their health plan before their IAHO hearing. Both beneficiaries who recalled receiving the packet and professionals who helped them reported that evidence packets were long, included complicated terms, and/or were difficult to understand. Because of the evidence packets' length and complexity, several beneficiaries said they did not read the entire packet and may not have been prepared to address questions about their case at the IAHO hearing.
- Beneficiaries who speak Spanish reported that their evidence packets were printed double-sided, with Spanish on one side and English on the other side, which made the packet longer and more difficult to understand.

"[The IAHO] sent me a letter. It was all in English. It said I had to call resources. I called all that and it was all in English. I don't speak English, so I stayed not understanding."

-Spanish-speaking beneficiary

"They [the IAHO] sent me a package that had 100 pages. I am not going to read all of that. I don't have the mental capacity for that. The information is in English and Spanish. I don't intend to read it. I don't know if I will need it for the hearing."

-Spanish-speaking beneficiary

User personas

Based on the information gathered from the interviews and summarized above, we created fictitious user personas for two types of beneficiaries navigating the appeals process. We defined the demographic characteristics for each user persona based on the average age of interviewees and most common types of appeals, and compared these characteristics with the level of support received to navigate the appeal process. Each persona is a fictitious synthesis of similar experiences across interviewees and does not reflect any one individual's experiences.

Exhibit 2. Fictitious user persona for high-touch beneficiary

Gloria

BACKGROUND

- Gloria is 75-years-old.
- Gloria is a native Spanish speaker.
- She has multiple chronic conditions and limited mobility.
- Gloria's appeal request is for additional support from a home health aide. Her Level 2 appeal was decided in her favor and she received the requested support.

A Day In The Life

Gloria lives alone in an apartment she owns. Gloria has one child, a daughter who lives close by and visits a few times a week when she has days off from work. Currently, Gloria receives 5 hours of personal care services daily. The aide arrives in the morning and helps Gloria with daily tasks and takes her to her doctors' appointments. The aide leaves after preparing lunch for Gloria. Gloria does her best to take care of herself during the afternoon and evening hours.

Overall, Gloria has been happy with her health plan, but recently encountered challenges in seeking additional hours in personal care services. Her health needs have become more complex and she struggles to do daily tasks at home like cleaning, dressing, bathing, and cooking. Gloria asks her health plan to extend her personal care services to 12 hours a day.

Experiences With Health Plan

Gloria received an adverse determination notice in **Spanish** and contacted her health plan with questions. The representative from the health plan informed her of the option to appeal and submitted the appeal request on her behalf.

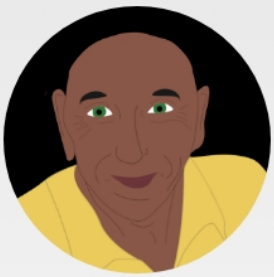
Experiences Navigating The Integrated Appeals Process

The evidence packet was originally provided in English. Upon realizing the beneficiary and daughter speak Spanish, the hearing officer requested the health plan send the packet in Spanish and re-scheduled the hearing to allow time to receive and review the packet. The packet was long, but Gloria's daughter reviewed some information with her. The health plan called the beneficiary to inform her of the re-scheduled hearing date and time.

Barriers Encountered Navigating The Appeals Process

The length of time between case forwarding and resolution of the Level 2 appeal request was five months. Gloria encountered challenges completing certain activities of daily living during the appeal period. Her daughter provided support some days after the home health aide. Both her daughter and an interpreter were present at the Level 2 hearing. Gloria had trouble answering some questions; her daughter responded on her behalf when needed.

Exhibit 3. Fictitious user persona for low-touch beneficiary



Derek

BACKGROUND

- Derek is 62-years-old.
- Derek is a native English speaker.
- He has multiple chronic conditions and behavioral health needs.
- Derek's appeal request is for additional support from a home health aide. His Level 2 appeal was decided in favor of the health plan and he did not receive the requested support.

A Day In The Life

Derek lives alone in an apartment. He has few family and friends who live close by. Derek manages several chronic conditions, is prone to seizures, and has behavioral health needs. He receives 5 hours of personal care services daily. The aide arrives each morning and helps him with cooking, cleaning, medications, and laundry. He experiences fatigue, dizziness, and low vision and has gone to the emergency room several times recently.

Derek does his best to take care of himself during the afternoon and evening hours. Derek believes he would benefit from support when attending medical appointments, doing errands, and while at home in the event he experiences a seizure. Derek requests that his health plan provide 3 additional hours in personal care services each day. Derek expressed limited awareness of the appeals process and a need for extra help to get through each day.

Experiences With Health Plan

Derek contacted his health plan to ask for an appeal for additional hours of personal care assistance that was not approved. He lives alone, currently receives support from a home health aide each morning and feels he would benefit from additional support in the afternoon. The representative from the health plan informed him of the option to appeal (via mail and phone) and he submitted the appeal request himself.

Experiences Navigating The Integrated Appeals Process

The hearing was held via phone; the hearing officer and a representative from the health plan were present. During the hearing, the health plan representative and hearing officer did not answer all of Derek's questions and did not address his confusion about the denied request. The hearing officer informed him that he would receive a determination in the mail. Derek reported that he sensed what the outcome of the hearing would be (denial).

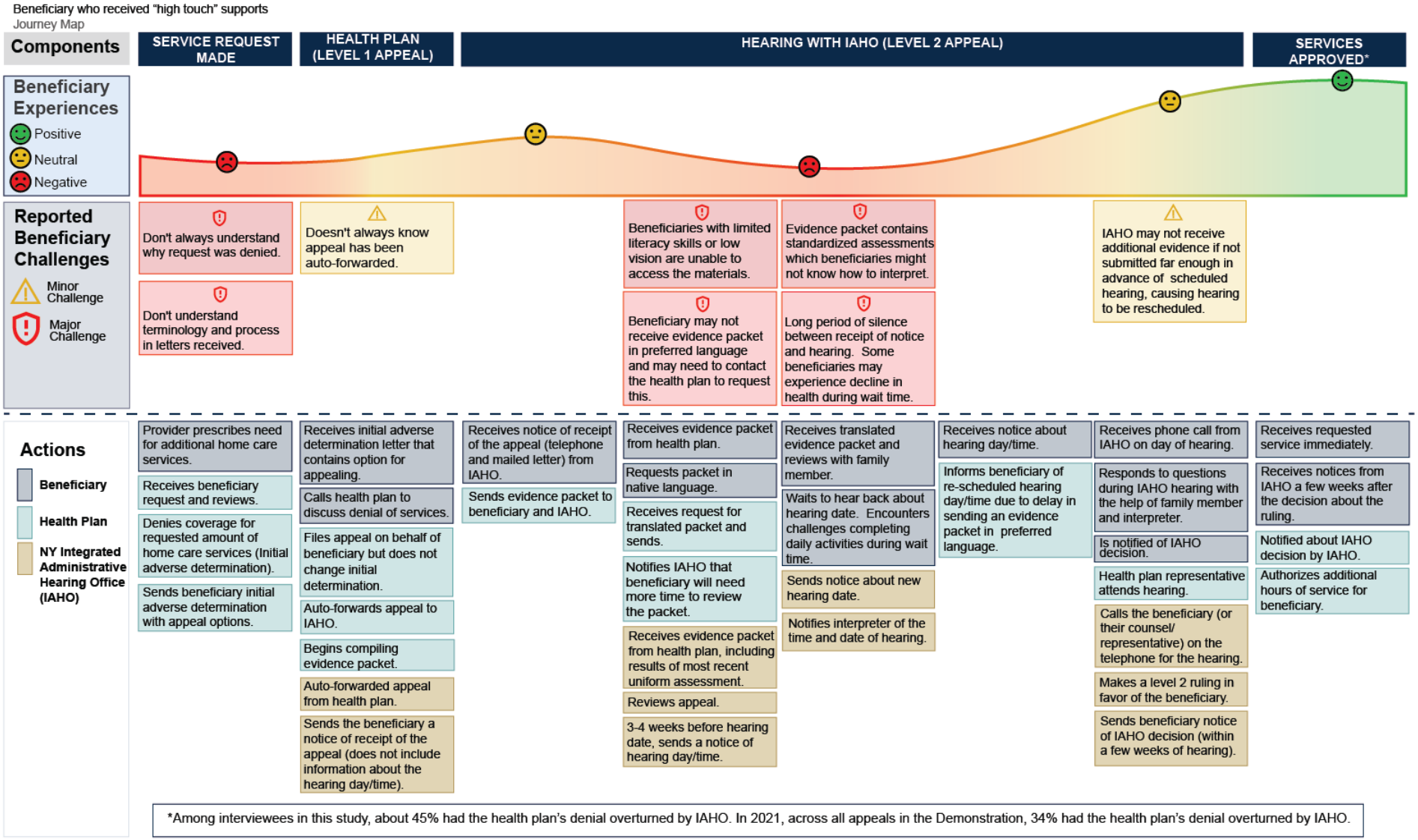
Barriers Encountered Navigating The Appeals Process

Derek did not recall receiving the evidence packet. He has trouble reading written material because of low vision. Derek has few informal supports and encountered challenges completing some activities during the appeal period, such as errands and medical appointments.

Journey Map

We also developed a journey map to graphically depict the beneficiary's experiences, reported challenges, and actions taken by the beneficiary, health plan, and IAHO at each level of the appeals process. In the journey map, "Beneficiary Experiences" captures beneficiaries' perception of their experiences with the integrated appeals process, and "Reported Beneficiary Challenges" summarizes areas in which beneficiaries thought they could use additional support. "Actions" describe the various actions the beneficiary, health plan, and IAHO take during the integrated appeals process. The journey map is a fictitious representation of experiences and challenges with the integrated appeals process based on Mathematica's analysis of interview findings.

Exhibit 4. Journey map for navigating the integrated appeals process



Possible Next Steps

Based on the most significant issues beneficiaries raised in the interviews, there are some potential opportunities to improve the beneficiary experience:

- **Care needs**. Health plan and state program managers could consider ways to ensure that beneficiaries have their care needs met during the period of time between the health plan's denial to the IAHO decision.
- **Communication.** It is important to keep all beneficiaries who file appeals informed of the status of their appeal. Beneficiaries could benefit from a single point of contact at the health plan to answer questions about the appeal process and/or status updates on a regular schedule while the appeal proceeds through the integrated system. Beneficiaries could opt for their preferred method of communication for these health plan status updates, including email, letter, text and/or phone call.
- **Access to information**. Beneficiaries may need additional support to fully understand and navigate the integrated appeals process. To improve their experience, beneficiaries may need improved access to information about each step of the appeals process, including information on how the appeals process works, the significance of the evidence packet, and how to access services during the appeals process.
- **Professional support**. To make the integrated appeals process more equitable for all beneficiaries, explore potential avenues to connect more beneficiaries with professionals who can assist them.

Limitations of Qualitative Research

Because of the qualitative nature of the research and small sample size, this study has the following limitations:

- Additional themes may have emerged from a broader or different sample of interviewees;
- Beneficiaries who chose to participate in this study may have felt more strongly about their interaction with the integrated A&G demonstration (positively or negatively) than beneficiaries who chose not to participate, so views of nonparticipants regarding integrated appeals may differ;
- The types of services appealed and the outcome of the appeals among study participants did not completely align with those across the demonstration. For example, study participants included those who had appealed personal care services, dental services, or requests for durable medical equipment, whereas the majority of appeals across the demonstration are for personal care services. Study participants were more likely to have their appeal decided in their favor;
- Although research questions were designed to understand beneficiaries' experiences with integrated appeals, it is possible that some did not recall the exact details of their appeals experiences; and
- Challenges identified by interviewees may not be unique to the demonstration. In previous research, individuals navigating the appeals process experienced stress, social isolation, and declines in health conditions while awaiting the hearing and managing their unmet needs, particularly if they required personal care assistance.[7]

[7] U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation (ASPE), Office of Disability, Aging and Long-Term Care Policy (DALTCP). "Beyond Fair Hearings: How Five States Help Medicaid Managed Care Beneficiaries Resolve Disputes with Health Care Plans." Washington, DC: ASPE/DALTCP, November 2001. Available at https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//112981/fairhear.pdf. Accessed June 25, 2022.