

## Executive Summary

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The Affordable Care Act (ACA)<sup>1</sup> Section 2703 established the Health Homes program to support the coordination of physical health, mental health, and social services with an emphasis on cost-effective whole-person care for Medicaid enrollees. The Health Home model allows people, including those with chronic medical problems, to manage their critical health care and other services through a specifically trained Care Manager. Rather than being a physical location, this innovative program is a virtual “home” or centralized point of contact for people to work with a care team to develop a person-centered plan of care. In July 2018, with Centers for Medicare & Medicaid Services (CMS) approval of New York’s State Plan Amendment #170025, the New York State (NYS) Department of Health (DOH) and the NYS Office for People With Developmental Disabilities (OPWDD) expanded the state’s Health Home Care Management program to serve individuals with intellectual and/or developmental disabilities (I/DD) through Care Coordination Organization/Health Homes (CCO/HHs).

The overall aim of New York’s CCO/HH program is to integrate care across multiple systems, including health and behavioral health, while engaging in proactive strategies to address barriers to care for people receiving services. The goals of the program are to:

- Improve preventative and transitional care;
- Reduce utilization associated with preventable inpatient stays (IP) and emergency rooms (ER) visits;
- Improve outcomes (e.g., relating to personal health, safety, and growth) for individuals with I/DD;
- Enable individuals to live and receive services in the most integrated and least restrictive settings; and,
- Enable individuals to have meaningful community participation and improve quality of life and health outcomes.

In August 2023, OPWDD selected the American Institutes for Research® (AIR®), together with its partners Precision Receivable Services and Aspell Services, Inc., through a competitive procurement process to conduct a program evaluation of the CCO/HH program. This program evaluation accompanies other OPWDD efforts, such as the CCO/HH Information Gathering (IG) Project, to assess the strengths and challenges of the program model and to make recommendations to promote the development of a statewide, comprehensive Quality

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<sup>1</sup> Refer to Appendix J for a full list of acronyms and their meanings.

Improvement Strategy for the CCO/HH program to address these challenges and improve population and enrollee outcomes.

## Evaluation Methodology

Three fundamental research questions guided this evaluation:

- What is the impact of the CCO/HH program on beneficiary health, well-being, and quality of life?
- How well is the CCO/HH program addressing the needs of high-need enrollees and special populations?
- What systemic factors influence program effectiveness, with a focus on deriving actionable recommendations for program quality improvement?

This evaluation team analyzed data from several primary and secondary data sources and conducted the following:

- A **document review**, which included previous analyses such as the results and findings from the OPWDD CCO/HH Information Gathering Project to gain an in-depth understanding of current policies, program requirements and processes, and Care Manager and provider roles and responsibilities.
  - Reviewed documents fell into three categories: (a) policy documents from OPWDD, NYS DOH, and CMS; (b) background materials, including program analyses, designation reviews, and workgroup feedback; and (c) resources that helped with the development of the survey and interview design, such as the CCO/HH Care Manager checklist. Extracted information was organized by key research domains, including beneficiary health impact, group-specific needs, program design, and improvement recommendations.
- An **enrollee and family survey**, to gather high-level information about different aspects of care management from the enrollee’s perspective:
  - OPWDD designed and disseminated the survey, with analysis conducted by the AIR team. The survey aimed to capture user perspectives on Care Management aspects like communication, satisfaction, policy implementation, and education to identify promising practices and barriers at personal and systemic levels. The survey was available on the OPWDD website from July 31 to August 26, 2024; reviewed for plain language by a peer specialist; and translated into New York State’s top 12 languages. Of 3,425 responses, 1,706 were complete.

- **Care Manager and provider survey**, to identify major themes and trends related to the adequacy of care coordination services and major barriers and challenges regarding service delivery under the program:
  - AIR conducted an online survey of CCO/HH Care Managers and both I/DD and non-I/DD providers through the Voxco platform from March to May 2024. The survey, developed using input from OPWDD and findings from prior reviews, was tailored to respondent roles within the program. Response rates were slightly less than 40% for Care Managers and around 10% for providers.
- **In-depth interviews** with the OPWDD leadership; CCO leaders; persons receiving CCO/HH services or their advocates and family members; the Executive Director of the Consumer Advisory Board (CAB) of the Willowbrook class members; and **focus groups** with Care Managers and self-advocates, to gather detailed insights and perspectives related to the effectiveness of CCO/HH program practices and recommendations for program improvement:
  - AIR conducted 12 interviews with OPWDD leadership; seven with CCO leaders (one per CCO); one with the CAB Executive Director; and 35 with enrollees, advocates, and family members. To recruit enrollees/advocates, OPWDD designated a CCO liaison for outreach, and AIR completed two rounds of recruitment. In addition, two focus groups were held with Care Managers and one with self-advocates. Data from interviews and focus groups were analyzed using structural and thematic coding to identify key themes and patterns.
- **Quantitative data analysis** of OPWDD datasets, including Life Plan Data Exchange/Care Coordination Data Definitions data, Coordinated Assessment System (CAS) data, and Medicaid claims, to describe the demographic characteristics and outcomes of the CCO/HH enrollee population and analyze the impact of CCO/HH program participation on health care utilization and expenditures:
  - AIR generated summary statistics (counts and percentages) for program experiments, by CCO/HHs and overall, for demographic characteristics and outcomes. Using a regression analysis, AIR estimated the impact of CCO/HH program participation on eight outcome measures of interest: (a) likelihood of ER visit, (b) number of ER visits, (c) likelihood of inpatient stay, (d) number of inpatient stays, (e) number of Home and Community Based Services (HCBS), (f) likelihood of Personal Care/Consumer Directed Personal Assistance Program (CDPAP) utilization, (g) total Medicaid payments (fee-for-service [FFS] only), and (h) OPWDD HCBS payments (FFS only).

## Key Highlights and Program Evaluation Conclusions

Overall, our evaluation identifies strengths and challenges with the current state of the CCO/HH Program using a multi-method approach that aims to integrate, interpret, and synthesize the quantitative and qualitative findings. As is consistent with multi-method research, findings may converge across respondents with similarities found in their perspectives and the reported results; however, they may also diverge. For example, diverging findings may be evident across a theme and reported as both a strength and a challenge depending on the viewpoints of the respondents.

In addition, the OPWDD CCO/HH IG Review Project was undertaken as a precursor to this program evaluation to supplement and inform this effort. The IG Report findings (which were based on in-depth case reviews as the predominant method) are referenced in this program evaluation as applicable. The full IG Report is located in [Appendix L](#).

### *Perspectives on Program Status and Benefits*

The CCO/HH program offers benefits to enrollees through a strengthened care coordination model, increasing access to essential services, and promoting long-term well-being. The following findings highlight the program's positive outcomes based on the data analyses:

#### Enhanced Health and Safety Outcomes

- **Fewer ER and inpatient visits:** Based on the quantitative data analysis, longer enrollment in a CCO/HH decreases the likelihood of ER and inpatient visits, reflecting improved health management and preventative care. Although this data is based on a relatively small number of people, it does provide supporting evidence to conclude that the program is making an impact pertaining to a key goal of the CCO/HH Program, 'to reduce utilization associated with preventable inpatient stays and emergency room visits.
- **Improved health and safety:** 65.1% of enrollees report feeling healthier and 67.8% report feeling safer as a result of the program's interventions.
- **Care Managers strive to provide timely support for urgent needs:** CCO/HHs have 24-hour access to assistance for enrollees. 52.6% of Care Managers report that individuals with urgent needs usually or always receive timely assistance minimizing the risk of potential crises from occurring. The type of assistance includes assessing the situation, calling emergency services if needed, engaging other parties and outreach to crisis, clinical or care planning teams. Providers disagree that Care Managers usually or always provide timely assistance.

## Increased Access to Services and Supports

- **Greater use of HCBS services:** Based on the data analysis, the longer individuals are enrolled in a CCO, the more likely they are to access a wide variety of HCBS, fostering independence and community integration.
- **Personal care and CDPAP accessibility:** Enrollees in the program for two or more years are significantly more likely to utilize personal care services and CDPAP based on the data analyzed.
- **Support for youth-to-adult transition:** 57.8% of Care Managers work with schools to understand a youth's need or inform them about their transition to adult services or employment. 63.8% of Care Managers engage with I/DD providers serving adults on transition planning for youth, and 47.7% of Care Managers work with enrollees and families/representatives to help youth learn about managing their health or dealing with decision-making and other skills to support transition readiness. Care Managers report a variety of activities to assist young enrollees in navigating the transition to adult services, ensuring continuity of care.

## Focused Care Coordination

- **Support for complex needs:** Care Managers report that individuals with higher or complex needs benefit from focused care coordination, including frequent contact (65.4% of Care Managers report that they usually or always contact enrollees more than the required minimum contacts), and 67.8% of Care Managers report conducting quarterly in-home visits where enrollees live. Care Managers also report on the need for frequent collaboration with I/DD providers and specialists. However, addressing and coordinating care specifically for complex health issues—such as, understanding medical terminology, managing individuals' medications, navigating health benefits or coverage, and understanding diagnoses—are particularly challenging for Care Managers. Care Managers expressed the need for more support and training regarding complex medical and behavioral issues.
- **Person-centered planning:** The person-centered planning process engages enrollees and their care teams and creates multiple opportunities for Care Managers to identify enrollees' needs and goals. 57.1% of enrollees feel that the care management service has met their needs and helped them access services they want and need; while 56.1% of enrollees felt that care management helped them reach their goals. This is compared to approximately 35.7% and 33.1%, respectively, of families/representatives who felt these areas were met by the care management service.
- **Culturally and linguistically competent care:** 77.6% of enrollees and 54.7% of family members report that they are happy or very happy with their Care Manager's ability to meet their communication needs including language translation/interpretation and

nonverbal communication methods. Additionally, 65.1% of enrollees and 66.8% of families/representative report that their Care Managers have met their cultural and linguistic needs and Care Managers would like to continue increasing their cultural and linguistic competence to do so.

- **Housing assistance:** Care Managers report that providing assistance to enrollees to find and maintain housing was one of their most challenging activities. Care Managers and providers are resourceful and creative in attempting to address enrollee housing options/concerns, particularly for individuals with high or emergency needs. But these efforts are not always successful due to the various systemic constraints that limit housing availability and/or access to housing. Care Managers engage in extensive communication, collaboration, and follow-up with providers and across systems to help enrollees transition to and maintain their preferred living arrangement whenever possible.

### Strengthened Relationships and Satisfaction

- **Empowered decision making:** Care Managers provide enrollees with the information needed to make informed decisions about their care, fostering autonomy and confidence. 69.7% of enrollees report that Care Managers provide enough information about their supports/services to make good decisions. Families/representatives have lower satisfaction at 40.0% with empowered decision-making.
- **Improved relationships, social and community engagement:** By connecting individuals through community activities, advocacy resources, and social opportunities, the CCO/HH program reduces social withdrawal and enriches lives. According to the data analysis, the longer individuals are enrolled in a CCO, the less likely they are to experience social withdrawal. The majority of enrollees have minimal or no social withdrawal based on the scale developed from OPWDD assessment data to measure a person's level of community participation. Additionally, the majority of individuals report Care Managers provide at least some help (always, very often, and sometimes) with being able to connect them with community activities.
- **Satisfaction levels:** Enrollees express satisfaction with their Life Plans (74.0%), Care Managers (72.9%), and the overall CCO experience (68.5%), appreciating the respect, attentiveness, and support provided.

### Collaboration and Innovation

- **Commitment to best practices:** The findings from this evaluation suggest that collaboration between CCOs and OPWDD supports the implementation of innovative, evidence-based approaches to care.

- **Leveraging technology:** Health IT platforms, electronic health records, and real-time alerts enhance communication and care delivery, to facilitate efforts to meet enrollees' needs effectively.

### Support for Providers and Families

- **Provider partnerships:** Providers work closely with Care Managers, leveraging shared records and clear communication to meet the needs of high-risk enrollees.
- **Family engagement:** Families and representatives are integral to decision-making processes, particularly for those directing their own care.

### Training and Guidance for Care Managers

- **Ongoing development:** CCO leaders report providing robust training and guidance, equipping Care Managers with the tools and knowledge needed to deliver high-quality support. Care Managers generally report having more than enough training but not always in the right focus areas.

### Program Barriers

The CCO/HH program encounters various obstacles to providing person-centered care for individuals with I/DD. These challenges arise from systemic, operational, and interpersonal factors, which collectively hinder the program's ability to address the diverse needs of its enrollees. Highlights of these concerns include:

**Socioeconomic and demographic differences:** The quantitative analysis found that high users of emergency or inpatient services are more likely to be Black, Native American, multiracial, or Hispanic (and less likely to be Asian) compared to non-high users. Non-Whites are also less likely than whites or multi-racial groups to have higher needs rate codes, and they are also less likely to be an HCBS user. Although the analysis identifies differences in utilization patterns between Whites and non-Whites, socioeconomic and demographic characteristics are only a part of the many factors that may explain differences in people accessing services. In addition, further work would be needed regarding the definition of marginalized communities and high-needs groups as this evaluation was limited to the available data. More focused analysis would be needed to determine the extent to which population disparities and health equity concerns may exist.

**Technology to support enrollee service delivery:** According to Care Managers, technology access and internet issues in certified residential settings can hinder telemedicine/ability to deliver remote services (only 20.7% of Care Managers reported that internet access in certified residential settings is always reliable). 58.4% of the Care Managers reported that enrollees lack the technology required to use telemedicine, and 53.1% of Care Managers reported that

enrollees have the necessary technology to use telemedicine but struggle to use it. I/DD providers corroborate this finding with 41.0% of I/DD providers identifying technology as a barrier to provision of remote supports, followed by 39.3% of I/DD providers who reported that enrollees do not have the physical technology for it.

**Technology and the CCO/HH program:** Opportunities to maximize the use of available platforms (e.g., electronic sharing of health information through qualified entities and existing state agency data applications), are not being fully leveraged. Furthermore, the IG Report noted the potential for technology solutions to support information sharing and timely access to pertinent documents, but there is significant variation across the state related to the efficacy of the information provided through the Regional Health Information Organizations (RHIOs)/Qualified Entities (QEs) connectivity available. Maximizing access to pertinent information is critical to ensuring that recommended interventions and supports are initiated timely and effectively to address the issues.

**Limited availability and lack of staff to support volunteer, recreational, and community engagement:** Care Managers struggle to link enrollees to services and supports that optimize desired volunteer, recreational and community engagement opportunities due to a lack of staffing for those programs. The availability of staff to support enrollees' desire for meaningful and engaging opportunities is a critical barrier. A shortage of staff, as well as their limited availability, is a common barrier to enrollees' participation in such activities.

**Impact of COVID-19:** The COVID-19 pandemic further disrupted service delivery, exacerbating existing challenges and underscoring the need for resilient systems and responsive care models.

**Delayed service access and community integration:** Enrollees and families report barriers to essential services like respite care, specialized medical care, behavioral health support, and crisis intervention. Long wait times, limited therapeutic opportunities, and geographic disparities, particularly in rural areas, worsen access issues. Similarly, respondents reported that systemic barriers around workforce shortages continue to impact the availability of services.

Families report that they also seek greater community participation through volunteer work, recreation, and employment, but Care Managers often lack the knowledge or connections to provide these opportunities, leaving many enrollees without meaningful engagement.

**Care management and service coordination:** Perceptions of Care Manager responsiveness and effectiveness vary, with concerns about limited supervisor support, poor communication, and lack of respect for enrollee privacy. Families feel that Care Managers often fail to provide



sufficient information, address complex questions, or respond promptly to updates and service requests. High Care Manager turnover and large caseloads worsen these issues.

Families also report challenges with CCO-OPWDD coordination, including inadequate support for understanding service options, maintaining benefits, and accessing programs like self-direction. The person-centered planning process is seen as lacking, with calls for stronger Life Plan development and goal achievement.

The role of the Health Home Care Manager and CCO/HH is not well understood by all stakeholders, especially providers of non-I/DD services. This challenge can impede information sharing and collaboration, impacting the effectiveness of care coordination. Additionally, relationships and collaboration between CCOs/Care Managers and I/DD providers need to be strengthened to improve the CCO/HH Program and quality of care. The IG Report also uncovered many instances of strained or ineffective relationships between Care Managers and HCBS providers impacting the communication and collaboration needed to effectively assist individuals with major challenges.

**Limited linguistic support:** Gaps in linguistic competence pose additional challenges, particularly for enrollees who use nonverbal communication or speak languages other than English. Providers and Care Managers need improved translation, interpretation, and other communication resources, tools, and training to better support enrollees' diverse verbal and nonverbal communication needs. Additionally, CCO/HHs should strive to hire Care Managers that speak the languages of their members.

**Operational and training gaps:** Care Managers report facing heavy administrative burdens, including extensive documentation and complex service authorizations, and anxiety around billing accountability and billing documentation, limiting their focus on person-centered planning and enrollee engagement. They also report inadequate training on medical and behavioral needs, cross-system referrals, and residential care policies. Non-I/DD providers' limited understanding of the I/DD service system further hinders collaboration.

**Care manager caseload size and burnout:** More Care Managers are uncomfortable than they are comfortable with the size of their caseloads. 51.8% of Care Managers reported they are uncomfortable with the size of their caseload compared to 41.4% who are comfortable. Care Managers with high caseloads find it difficult to document interactions promptly. They often cannot enter notes in real time, leading to a backlog and additional stress. Both Care Managers and enrollees report that smaller caseloads would allow for increased person-centeredness and increased quality of care. Additionally, supervisors who carry caseloads was noted as an issue by Care Managers, as these supervisors are not able to effectively support the Care Managers they are supposed to be supervising. Geography in rural areas necessitating travel time was

also cited by Care Managers with large caseloads as compounding the challenges. Care Managers reported feelings of burnout nearly twice as much as providers. 67.4% of Care Managers reported feelings of burnout and given that the Care Manager survey response was 40% this is a significant data point. As a comparison, 33.3% of I/DD providers reported feelings of burnout and 37.9% of non-I/DD providers reported the same. Caseload size is compounded by high Care Manager turnover and administrative work and travel burdens; all these factors contribute to feelings of burnout among Care Managers.

### ***Key Challenges and Recommendations***

Overcoming the challenges within the CCO/HH program demands a holistic approach centered on equity, systemic and programmatic improvements, and strengthened training and support for Care Managers. The recommendations target the major barriers that affect program effectiveness, emphasizing better communication, streamlined administrative processes, increased community integration, and enhanced use of technology. These strategies are intended to ensure the program delivers person-centered care and serves its diverse population effectively. [Exhibit ES.1](#) summarizes the key challenges derived from the evaluation and identifies the stakeholder group(s) that contributed to specific findings.

### **Delivery of Care Management/Care Coordination Services**

Key challenges in service delivery include the need for Care Managers to adopt a more proactive and leadership-driven approach, actively coordinating care and advocating for enrollees. Transitioning from youth to adult services is particularly problematic, with limited early planning; insufficient collaboration among families, schools, and providers; and a lack of long-term planning, causing delays and stress. Enrollees with co-occurring mental health and developmental disabilities face significant barriers because of providers' limited capacity to address dual diagnoses, inadequate coordination between specialists, and confusion regarding responsibility for complex cases. Systemic inefficiencies in service approval and eligibility processes, including inconsistent criteria and unclear denials, further delay access to necessary services, creating frustration for enrollees, families, and Care Managers.

## Exhibit ES.1. Overview of Key Challenges and Recommendations Related to the Delivery of Care Management Services

Key challenges	Advocates*	Care Managers*	CCO leadership*	Enrollees*	Families/representatives*	I/DD providers	Non-I/DD providers	OPWDD leadership
<b>Delivery of services</b>								
1. Need for Care Managers to take a more proactive approach	●			●	●	●	●	●
2. Support for transitions to adulthood		●			●			
3. Access to services for individuals with co-occurring/complex needs		●			●	●	●	●
4. Systemic challenges in service approval and eligibility processes	●	●	●					

\* Indicates an audience that is represented by more than one data source (e.g., Care Managers could have completed the Care Manager survey and participated in a Care Manager focus group).

### Recommendations

- **CCOs** should develop a comprehensive training curriculum to strengthen Care Managers' service system knowledge and capacity to proactively support and monitor enrollees. The training should cover all available services, eligibility criteria, processes for accessing these services, and processes for monitoring enrollees' service access and use.
- **CCOs** should develop and provide an easily accessible digital library of resources, including quick-reference guides, service directories, and eligibility checklists, updated monthly.
- **OPWDD, DOH, and CCOs** should conduct a comprehensive audit of current IT systems used for Care Management. This audit should identify gaps in interoperability, user interface issues, and barriers to timely data access.
- **OPWDD and CCOs** should work together to identify opportunities to engage in transition planning earlier in the process.
- At the outset of the transition planning process, **OPWDD and CCOs** should ensure that **Care Managers, enrollees, and families** are introduced to the **NYS Employment First initiative**. Emphasize the importance of **competitive integrated employment** as a primary goal.
- **CCOs** should develop and maintain a centralized database of programs to reference, such as Day Habilitation, Community Habilitation, postsecondary education, and employment services for CCO staff, enrollees, and enrollees' families/representatives.

- **OPWDD and CCOs** should work together to implement training for Care Managers to actively work with youth on self-advocacy, decision making, and the self-care skills necessary for adulthood.
- **OPWDD and CCOs** should work together to create a detailed roadmap outlining the steps in the transition process, broken into phases (e.g., early planning, skill building, program enrollment, postsecondary transition).
- **CCOs** should form dedicated transition support teams within CCOs to guide enrollees and families through complex transitions.
- **OPWDD** should coordinate and provide learning and development opportunities for providers, Care Managers, and other service systems to equip professionals working with the CCO/HH program to support individuals with I/DD, particularly individuals with complex or cross-system needs (e.g., behavioral supports, mental health services).<sup>2</sup>
- **OPWDD** should lead the charge in helping CCOs collaborate with behavioral health and developmental disability experts to design training materials that focus on best practices for managing co-occurring mental health and developmental disabilities.
- **OPWDD and CCOs** should jointly design a detailed framework that defines the roles and responsibilities of Care Managers, providers, and other team members. Ensure the framework accounts for the role of Crisis Services for Individuals with Developmental Disabilities (CSIDD) providers and service requirements, including protocols for crisis response, ongoing behavioral health support, and family engagement for improved coordination between CCOs and CSIDD providers as recommended in the IG Report.
- **CCOs** should clearly and systematically document the requirements for service approvals—particularly for justifications—to help Care Managers address them. CCOs’ and Care Managers’ lack of clarity on service justifications and requirements indicates the need for additional training and collaboration between OPWDD and CCOs to improve the submission Request for Service Authorization (RSA) and the implementation of the Service Amendment Request Tool (SART), as recommended by the IG Report.
- **OPWDD** should continue facilitating regular forums between OPWDD and CCOs, such as biannual workshops, monthly meetings, or a shared online community to discuss updates and issues with SART and ensure consistent implementation across regions.
- **OPWDD** should create an accessible knowledge base for SART-related resources, including FAQs, instructional videos, and a live help desk.

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<sup>2</sup> Anxiety disorders, depressive disorders, attention-deficit/hyperactivity disorder, autism spectrum disorder, bipolar disorder, psychotic disorders, substance abuse disorders, personality disorders, impulse-control disorders, and more.

- **OPWDD** should create a standardized set of criteria for service approvals, applicable across all regions, to reduce inconsistencies. Include clear thresholds for approval and denial.
- **OPWDD** should develop standardized templates for OPWDD staff to complete that includes detailed explanations for why RSAs or SARTs cannot be approved when submitted outlining what additional information is needed to support the justification for needed services and why, listing any missing documentation, and any other specifics that will help the Care Managers to resubmit the needed information for approved processing.
- **OPWDD** should continue its efforts to implement an automated system that sends reminders for pending approvals or incomplete paperwork to Care Managers and approvers.

### Person-Centered Planning

Person-centered planning faces several challenges, including the rigidity of Life Plan tools, which rely on dropdown menus that limit customization and fail to capture individualized needs. This lack of flexibility often leads to “cookie-cutter” plans that do not fully reflect enrollees’ unique circumstances. Care Managers also struggle with large caseloads and ongoing policy updates, reducing their capacity to build meaningful relationships with enrollees. Exhibit ES.2 summarizes key challenges related to person-centered planning.

### Exhibit ES.2. Overview of Key Challenges and Recommendations Related to Person-Centered Planning

Key challenges	Advocates*	Care Managers*	CCO leadership*	Enrollees*	Families/ representatives*	I/DD providers	Non-I/DD providers	OPWDD leadership
<b>Person-centered planning</b>								
1. Need for more personalized care	●	●		●	●			●
2. Limitations that restrict effective planning	●	●	●	●	●			
3. Challenges with non-I/DD providers		●						

\* Indicates an audience that is represented by more than one data source (e.g., Care Managers could have completed the Care Manager survey and participated in a Care Manager focus group).

## Recommendations

- **OPWDD** should consider leading an effort to convene a joint task force of CCOs, Care Managers, and OPWDD representatives to systematically review the Life Plan tool.
- **CCOs** should create a secure, centralized database or online repository where Care Managers can upload and access examples of highly personalized Life Plans (with anonymized data to protect privacy).
- **OPWDD** should continue to support CCOs in establishing communities of practice among CCOs to share and develop best practices, lessons learned, and resources that support effective and personalized planning.
- **OPWDD** should establish a formal feedback loop process among OPWDD, providers, and Care Managers to identify and resolve conflicts between regulatory requirements and person-centered goals. Use this feedback loop to advocate for ongoing policy reform.

## Service Access

Service access challenges include barriers in connecting enrollees to limited resources such as housing, health care, and employment, leaving many needs unmet. For example, the limited availability of housing opportunities that are certified, non-certified or align with enrollees' personal interests is the most often reported barrier to enrollees transitioning to their preferred living arrangement as reported by both Care Managers and I/DD providers. Care Managers struggle with inconsistent cross-system referrals, provider shortages, and delays in accessing specialized services, particularly for people with complex conditions. In addition, limited integration and data-sharing between I/DD and non-I/DD providers hindered by HIPAA restrictions and outdated documentation practices obstruct effective care coordination. The Life Planning process can be unreliable depending on a variety of factors (e.g., timeliness of information sharing) and may result in the Life Plan failing to reflect current enrollee needs, further complicating service delivery. Communication breakdowns among enrollees, families, providers, and Care Managers exacerbate these issues, causing delays and dissatisfaction. Exhibit ES.3 summarizes key challenges related to service access.

### Exhibit ES.3. Overview of Key Challenges and Recommendations Related to Service Access

Key challenges	Advocates*	Care Managers*	CCO leadership*	Enrollees*	Families / representatives*	I/DD providers	Non-I/DD providers	OPWDD leadership
<b>Service access</b>								
1. Challenges connecting enrollees to services	●	●	●	●	●			
2. Challenges with cross-system referrals to medical and behavioral health services		●				●	●	
3. Access to enrollee records and Life Plan documentation		●	●			●	●	
4. Communication barriers	●	●		●	●	●	●	

\* Indicates an audience that is represented by more than one data source (e.g., Care Managers could have completed the Care Manager survey and participated in a Care Manager focus group).

#### Recommendations

- **OPWDD** should explore how to expand the array of or otherwise enhance access to both certified and non-certified housing options and providers, particularly to accommodate enrollees with a range of need levels. An expansion of housing and support options and/or greater expertise in housing navigation by the CCOs will better enable Care Managers to successfully assist enrollees in finding their preferred living arrangement in the most integrated setting appropriate to the enrollee’s needs.
- **CCOs** should provide specialized training and resources for Care Managers on navigating federal, state, and local housing assistance programs. CCOs should also develop a centralized housing assistance database or toolkit that includes step-by-step guides for applying to these programs, ensuring that enrollees can live in their preferred arrangements.
- **OPWDD and CCOs** should implement regular joint planning sessions with service providers to map service availability across regions and identify critical service gaps. These sessions should inform the development of strategic plans, including setting measurable goals for expanding service access (e.g., increasing the number of providers in underserved areas by 10% within two years).
- **OPWDD and CCOs** should create user-friendly tools and resources, such as standardized referral guides, workflow templates, and referral monitoring dashboards, designed to integrate seamlessly into providers’ and CCO clinical team members’ existing processes.

- **OPWDD and CCOs** should collaborate with clinical experts to design targeted training programs for providers and specialists on managing dual diagnoses. These programs could include in-person workshops, on-demand webinars, and case-based learning modules focused on practical strategies, evidence-based interventions, and multidisciplinary approaches to care.
- **OPWDD and CCOs** should establish a framework that clearly defines roles and responsibilities, prioritizing communication and collaboration across teams. Ensure that CSIDD providers and service requirements are aligned with this specialized behavioral health service to build a strong, consistent foundation for those with complex needs.
- **OPWDD and CCOs** should evaluate the implementation of a portal solution to increase access to pertinent records and to share Life Plans and other support plans in real time between CCOs and Providers as timely access is critical to provision of timely and effective intervention.
- **OPWDD and CCOs** should establish a standardized protocol for sharing enrollee information among I/DD providers, non-I/DD providers, and Care Managers. This could include creating secure, web-based communication portals or using existing health information exchanges for real-time updates.
- **OPWDD** could consider hosting roundtable discussions involving CCOs, hospital administrators, and dental providers to identify specific barriers to information sharing, such as technical incompatibilities, legal concerns, or workflow inefficiencies.
- **OPWDD** should help CCOs negotiate agreements with providers to grant Care Managers read-only or editable access to EHR systems while ensuring compliance with privacy laws.
- **OPWDD** might consider creating a centralized communication platform, such as a dedicated portal or email newsletter, for disseminating updates and policy changes.
- **OPWDD** should distribute semiannual surveys to Care Managers, enrollees, families, and providers to gather feedback on communication quality and identify challenges.
- **OPWDD** might consider requiring each CCO to designate a “Communication Liaison” responsible for coordinating updates, addressing stakeholder inquiries, and managing feedback from enrollees, families, and providers.
- **CCOs** should develop and enforce response time standards for addressing inquiries and providing follow-ups, such as a 24-hour acknowledgment window and resolution within a given time frame.



## Social Engagement and Enrichment Opportunities

Enrollees face barriers to meaningful community participation, skill-building, and employment opportunities, which are critical for personal growth, social interaction, and independence. The CCO/HH program’s emphasis on medical needs often leaves social and relational needs underserved. Limited access to practical skill-building programs (e.g., travel, budgeting, cooking) and enriching activities like art therapy or recreational opportunities restricts personal and emotional development. Systemic issues, such as staffing shortages, unclear service authorizations justification requirements, and resource shortages, exacerbate these challenges, particularly for older enrollees seeking active engagement, and families of younger enrollees seeking cognitively stimulating respite services. Exhibit ES.4 summarizes key challenges related to social engagement and enrichment opportunities.

### Exhibit ES.4. Overview of Key Challenges and Recommendations Related to Social Engagement and Enrichment Opportunities

Key challenges	Advocates*	Care Managers*	CCO leadership*	Enrollees*	Families / representatives*	I/DD providers	Non-I/DD providers	OPWDD leadership
<b>Social engagement and enrichment opportunities</b>								
1. Social engagement through community participation and paid employment opportunities	●	●		●	●			
2. Need for more skill-building and therapeutic opportunities	●	●		●	●			

\* Indicates an audience that is represented by more than one data source (e.g., Care Managers could have completed the Care Manager survey and participated in a Care Manager focus group).

### Recommendations

- **OPWDD** to help CCOs develop a user-friendly, searchable online platform where Care Managers can access up-to-date information on available services, programs, and supports. Include filters by location, eligibility, and enrollee preferences.
- **CCOs** should form agreements with social clubs, recreation centers, and cultural organizations to offer discounted or free programs for enrollees, such as art classes, fitness programs, and cultural festivals.
- **CCOs** might consider establishing stronger connections between Care Managers and local employers to create job opportunities that align with enrollees' interests and skills,

fostering both personal growth and financial independence. Develop a database of local employers interested in hiring individuals with I/DD.

- **CCOs** should develop specialized roles within CCOs focused exclusively on helping enrollees achieve their employment goals.
- **OPWDD and CCOs** should collaborate to develop tailored frameworks for addressing social needs by age group (e.g., early childhood, adolescence, adulthood, and senior years). Include specific goals, such as improving peer interactions in childhood, fostering independence in adolescence, and reducing isolation in senior years.
- **CCOs** should create and maintain a centralized database of local and virtual social skill-building programs, recreational activities, and community events. Include filters for age, skill level, interests, and accessibility.
- **Care Managers** should ensure that enrollees have the necessary information and resources regarding skill building, training, and employment consistent with New York’s Employment First initiatives. In addition, Care Managers should be working with OPWDD to actively seek job readiness and volunteer opportunities, as well as paid competitive employment opportunities for those who identify employment as a desired goal/outcome in their Life Plan during the person-centered planning process.

### **Administrative Burdens and Operational Complexities**

The CCO/HH program faces significant challenges because of the administrative burdens placed on Care Managers, who spend much of their time on paperwork and documentation (more than three-quarters of Care Managers report sharing or obtaining documentation from providers and enrollees take up a moderate or high amount of time; more than half of I/DD providers report the same), leaving limited capacity for meaningful enrollee engagement. High caseloads exacerbate staff burnout and turnover, further reducing care quality and consistency. Frequent regulatory updates disrupt services and require constant adjustments, adding to Care Managers’ workload. There is also a need for enhanced training in cultural and linguistic competency, including topics like diversity, equity, and inclusion (DEI), social determinants of health; and communication methods such as American Sign Language (ASL) and Braille, to better support enrollees from diverse backgrounds. Exhibit ES.5 summarizes key challenges related to administrative burdens.

## Exhibit ES.5. Overview of Key Challenges and Recommendations Related to Administrative Burdens and Operational Complexities

Key challenges	Advocates*	Care Managers*	CCO leadership*	Enrollees*	Families / representatives*	I/DD Providers	Non-I/DD providers	OPWDD leadership
<b>Administrative burdens and operational complexities</b>								
1. Administrative tasks impede person-centered planning and quality of care		●	●	●	●			●
2. Frequent programmatic and regulatory updates disrupt services	●	●	●					
3. Care Manager caseload issues and staff burnout		●	●	●	●	●	●	●
4. Need for additional training on cultural and linguistic competency	●	●	●			●	●	

\* Indicates an audience that is represented by more than one data source (e.g., Care Managers could have completed the Care Manager survey and participated in a Care Manager focus group).

### Recommendations

- **CCOs** should provide Care Managers with tools and training to complete administrative tasks more effectively and efficiently.
- **CCOs** should consider expanding the administrative support teams by hiring additional staff specifically to assist with nonclinical tasks.
- To help CCOs plan, **OPWDD** should develop a timeline or roadmap that projects the release of upcoming Administrative Memoranda (ADMs). OPWDD should consider creating a rolling 12-month calendar that outlines projected release dates for upcoming ADMs, updates, and policy changes.
- **OPWDD should coordinate with CCOs** to provide mandatory, 30- to 60-minute webinars or in-person sessions within 2 weeks of any significant ADM release. Include real-world case studies or scenarios to demonstrate how the changes apply in practice.
- **OPWDD** should finalize its work on maintaining updated, easy-to-navigate digital manuals that automatically integrate regulatory changes, reducing the burden of manual policy adjustments for CCOs. Integrate real-time updates to reflect changes in regulations, policies, and procedures, ensuring that all users have access to the most current information.

- **OPWDD** could establish and enforce maximum caseload standards, factoring in the complexity of enrollees' needs. OPWDD should consider conducting a comprehensive study to determine maximum caseload limits based on enrollee needs and complexity, categorizing cases into tiers (e.g., high, moderate, and low complexity).
- **CCOs** could provide emotional and professional support for Care Managers (e.g., for peer support groups). Partner with employee assistance programs to provide confidential counseling services for Care Managers.
- **OPWDD and CCOs** should offer professional development opportunities and recognition programs to increase retention. Create monthly or quarterly awards recognizing exceptional performance, innovative practices, or high-quality service delivery by Care Managers.
- During periods of high turnover, **CCOs** should implement temporary measures, such as bringing in float staff or assigning administrative support staff, who can help ensure that Care Managers' caseloads remain manageable.
- **OPWDD** should implement or partner with medical and public health schools to conduct mandatory training on DEI, focusing on social determinants of health, gender orientation, religious customs, and strategies for culturally sensitive care.
- **OPWDD and CCOs** should provide access to language classes for ASL, Braille, Spanish, Korean, Arabic, Yiddish, and other languages commonly spoken among enrollees. Include training on the use of assistive communication devices like iPads, teletypewriters, and Picture Exchange Communication Systems (PECS) for individuals who do not use speech but can point to pictures to express their feelings and needs.
- **CCOs** should invest in language access services, such as translation and interpretation. This should include technology that is reliable and user friendly, such as on-demand video remote interpretation, portable translator apps, and PECS individuals who do not use speech.

### **Understanding and Navigating the Service System**

The CCO/HH program faces challenges in care coordination because of gaps in understanding the service system and lack of understanding of the role of Care Managers and CCO/HHs. This role confusion can hinder effective care management and lead to barriers in critical information sharing needed for timely intervention. Enrollees and families seek more knowledgeable and proactive Care Managers to recommend suitable services and resources. However, many Care Managers struggle with connecting enrollees with appropriate services despite identifying their needs. While I/DD providers have stronger engagement with the program, non-I/DD providers often lack familiarity with its processes, hindering collaboration and integrated care. Exhibit ES.6 summarizes key challenges related to understanding the service system.

## Exhibit ES.6. Overview of Key Challenges and Recommendations Related to Understanding and Navigating the Service System

Key challenges	Advocates*	Care Managers*	CCO leadership*	Enrollees*	Families / representatives*	I/DD providers	Non-I/DD providers	OPWDD leadership
<b>Understanding and navigating the service system</b>								
1. Need for improved care coordination capacity		●	●	●	●	●	●	●
2. Provider engagement and knowledge gaps		●	●			●	●	●

\* Indicates an audience that is represented by more than one data source (e.g., Care Managers could have completed the Care Manager survey and participated in a Care Manager focus group).

### Recommendations

- **OPWDD** should educate Care Managers about the OPWDD service system more comprehensively beyond specific requirements or other programmatic changes.
- When implementing programmatic changes, **OPWDD** should accommodate lead time that allows CCOs to train Care Managers and other staff and formally incorporate them into practice.
- **OPWDD and CCOs** should incorporate enrollees', families', and representatives' understanding of the service system and their service options for entry into care coordination by equipping Care Managers with the knowledge and resources to educate enrollees, families, and representatives about their services.
- **OPWDD and CCOs** could increase Care Managers' capacity to connect enrollees with services, not just identify their needs, and support collaboratives in which staff can share lessons learned, best practices, and resources. Implement peer learning groups where Care Managers can regularly discuss challenges, share best practices, and exchange resources.
- **OPWDD and CCOs** should collaborate with subject matter experts, including Care Managers and OPWDD, to develop a comprehensive training curriculum. Create modules explaining the structure, objectives, and benefits of the program, emphasizing how it aligns with broader health care and social services for individuals with I/DD.
- **CCOs** might consider creating a provider shadowing program in which non-I/DD providers can spend time with Care Managers in the field, observing their day-to-day tasks, challenges, and decision-making processes.

- **OPWDD** could help CCOs develop a centralized digital platform where both I/DD and non-I/DD providers can access real-time information about enrollees' needs, care plans, and available services.
- **CCOs and Care Managers** should involve non-I/DD providers in strategic planning and decision making within CCOs.
- **CCOs** should create easy-to-understand, step-by-step guides that walk non-I/DD providers through key aspects of the CCO/HH program, including FAQs that address common confusions or misconceptions about the program.

### ***Summary Conclusions***

This evaluation sets out to learn about the current state, strengths, and challenges of the CCO/HH program, six years into its operation, to provide insights and recommendations for New York State to focus program improvement efforts. The evaluation used a multi-method approach combining quantitative and qualitative methods. AIR synthesized and interpreted the data from various stakeholder perspectives and organized the results in Chapter 5 within three primary research questions that include the impact of the program particularly for high-need enrollees and special populations; and systemic factors impacting the program's overall effectiveness. We then synthesized our findings and recommendations in Chapter 6.

The evaluation uncovered positive aspects of the program and areas needing improvement within the same topic areas. For example, quantitative analysis indicates that the longer people are enrolled in the CCO/HH program the greater their use and access to HCBS services. At the same time, the evaluation also shows that enrollees and families want/need greater access to respite and other HCBS services that are constrained due to limited staffing availability. The multi-method approach along with varying stakeholder and data perspectives expands the scope of information available to OPWDD and CCOs to better understand the state of the program and target areas that are most important and will be most impactful to continuous quality improvement. Further study of these areas and the root causes of stakeholder feelings and perspectives, including contributing factors, would be beneficial to improving the quality of the program.

The evaluation's quantitative findings highlight the program's success in reducing emergency room visits and inpatient stays, increasing access to a broad range of services, including personal care and reducing the risk of social withdrawal the longer people are enrolled in a CCO/HH.

The qualitative findings indicate that the majority of enrollees are satisfied with their Life Plan, their Care Manager, their CCO/HH services, their Care Manager's ability to meet their communication needs including language translation and interpretation and their Care

Manager's provision of enough information to support enrollee decision-making. Most enrollees also reported that Care Managers help them to meet their needs and reach their goals and they feel healthier and safer because of engaging in care management services. Family members and representatives expressed satisfaction in some of these areas but generally are less satisfied than enrollees and view care management performance less favorably in many areas than enrollees. This divergence would be useful to study in the future to gain a better understanding of these results and to rule out any response biases, such as whether enrollees who completed the individual survey were more independent and therefore more satisfied with their lives while family/representatives were completing the survey on behalf of loved ones who were less able to speak for themselves and/or are complex or in need of cross systems supports that are more difficult to navigate and obtain.

There are also additional areas where respondents had varying viewpoints. There was an overwhelming consensus that person centered planning is an important value across the system. However, there were mixed perceptions on whether person-centered planning is being fully carried out due to concerns with the focus on documentation and compliance as well limitations with the Life Plan template, and lack of availability of opportunities, staffing, and services.

Providers typically had lower perceptions of Care Managers' ability to address community participation (e.g., employment, volunteering, or individuals' dissatisfaction with opportunities for community participation). Perceptions regarding whether Care Managers were helpful in supporting cross-system service coordination were also mixed across Care Managers and providers. For high-need enrollees, almost half of Care Managers generally indicated that providers were usually able to accomplish what Care Managers needed them to do. However, only 38% of I/DD providers felt that Care Managers were usually able to accomplish what enrollees needed. Overall, the relationship between Care Managers/CCOs and I/DD providers needs to be strengthened to improve the effectiveness of the program. Care Managers also expressed that non-I/DD providers have less understanding of the I/DD system and are often challenging to contact.

There is agreement on the need for more training, better communication and greater understanding of roles and responsibilities as well as policies and procedures. Additional challenges identified include staffing, Care Manager and provider turnover, Care Manager caseload sizes and regulatory and administrative burdens. While highly committed and believe the work is rewarding, the majority of Care Managers report feelings of burnout as well as an additional burden of frequent changes in regulations and requirements with continuous re-training. High caseloads and turnover are also contributors to burnout.

The recommendations outlined in this report aim to address challenges by enhancing Care Manager training, clarifying roles and responsibilities of various system stakeholders, fostering

greater collaboration between CCO/HHs and Providers and across systems including non-I/DD providers, leveraging technology, and improving systemic barriers to optimize the program's effectiveness. These insights offer a comprehensive understanding of the program's impact and pathways for continuous improvement.

While there are various limitations to this study including time constraints, sample sizes, lack of ability to conduct longitudinal analysis, etc. (described in Chapter 3), this program evaluation does form a foundation on which to consider various potential improvements and to undertake further study in important domain areas.