



Office for People With
Developmental Disabilities

Care Coordination Organization Program Evaluation Report

By American Institutes for Research



April 2025

Plain Language

Overview:

The Affordable Care Act is a law that created the Health Homes program to help coordinate physical health, mental health and social services for each person with a developmental disability receiving OPWDD services.



Care Coordination Organizations (CCOs) were opened in 2018 to provide care management to people with developmental disabilities through the Health Homes program.

Since 2018, Care Managers who work for Care Coordination Organizations have helped New Yorkers with developmental disabilities plan the services they get from developmental disabilities providers, healthcare providers and mental health providers.

Care Managers help people get services in the place that is most comfortable for them. They also help people be a part of their communities and have a better, more healthy life.

Program Review:

In 2023, OPWDD asked a research group, American Institutes for Research, to review OPWDD's CCO program to find out what is good about the program and what could be better. This information will be used to help make the support people get from their Care Managers better.



The review of the CCO program looked at three things:

- Does the CCO program make people healthier and their lives better?
- How well does the program help people who need the most help?
- What can we learn from the review to make the CCO program work better for people?



The Review included:

- Review of policy and program documents.
- A survey of people who use the program and their families.
- A survey of people who provide the program, such as Care Managers and the people they work with to plan services.
- Interviews with people who use the program, their family members and advocates, and other people who provide or oversee services.
- Review of the data around who uses the program and how it is affecting their life and services.



Overall, the review showed strengths and challenges with Care Coordination Organizations' delivery of the program.



Strengths

Enhanced Safety and Outcomes

The review by American Institutes for Research reported that people enrolled with Care Coordination Organizations are spending less time in emergency rooms and feel healthier the longer they are enrolled.

Care Managers report that people who need supports the most and those with the greatest needs are getting assistance when they need it.



Increased Access to Services & Supports

People are using Home and Community Based Services more, leading to greater independence.

The longer someone is enrolled in the program, the more likely they are to use personal care services.

Care Managers are also reportedly working closely with people leaving high school to help them find services as an adult.

Focused Care Coordination

People with complex medical and behavioral needs benefit from focused care coordination.

More than half of people surveyed felt their needs were being met and that their Care Managers were helping them get the support they want and need.

More than half of people surveyed also felt that their communication needs were being met using the correct communication methods, whether using translations or non-verbal communications.



Strengthened Relationships and Satisfaction

People reported feeling that they were able to make their own decisions about their care.

People say they are happy with their services and able to take part in activities with others.

Collaboration and Innovation

The report finds that when CCOs and OPWDD work together, new ideas and better care are the result.

Electronic health records and other online platforms help providers to better meet people's needs and produce positive outcomes.

Support for Providers and Families

Providers work closely with Care Managers to produce the best outcomes for people with the highest needs.

Families and other support people are an important part of the decision-making process, especially for people who self-direct their services.



Training and Guidance for Care Managers

According to CCOs, Care Managers are receiving the training and guidance that they need, however Care Managers report that they would also like to receive more training on different topics.

Challenges

Cultural barriers

The report mentions differences in how services are used by groups of people from different backgrounds. For example, high users of emergency services are likely to be Black, Native American, multiracial or Hispanic.

Some families said using services through CCOs and OPWDD can be hard to understand, especially self-direction.

The report finds that more study is needed to determine if there are equity concerns.



Technology issues

Some people have problems using the Internet and other technology that shares people's health data.

Technology solutions are not being used to their full potential.

There are differences in how information is exchanged between organizations which slows things down.

Staffing Concerns

People feel there is not enough staff to help people do activities they want to do.

Difficulty finding care for people in crisis and difficulty getting breaks for caregivers was reported.



COVID-19

COVID-19 caused changes in the way people were getting their services, which made problems that already existed worse.

Delayed Access to Services

Long wait times and limited services for respite, medical care, behavioral health support and crisis support make it difficult to get needed support.

Lack of staff makes it even more difficult for people to get the services they need when they need them.

Care Managers don't have the connections or knowledge to help people access activities in their communities.

Care Management

Poor communications and lack of respect for privacy by Care Managers were reported by some people who receive services.

Some families said that their Care Manager does not get back to them fast enough and they don't hear from them as much as they should.

Some families find that Care Managers are not providing enough information, are not able to answer hard questions and are not responding to requests for services fast enough.

Families think the Life Plan process should be better at helping people reach their goals.

Care Managers don't always know what is available to people who want things to do things in their communities.

Care Managers are reported to not have enough supervisor support.

The role of the Care Manager is also not well understood by people who use the service.

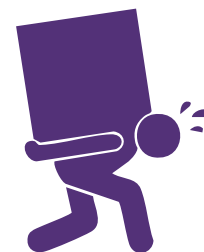
The report also said that Care Managers need to do better at communicating with people who don't speak English or people who don't speak at all when they communicate.

Care Manager and Caseloads

Care Managers have heavy burdens like a lot of paperwork and responsibility for billing correctly that take their attention away from person-centered planning.

Each Care Manager is helping too many people and having a smaller number of people to support would help Care Managers focus more on supporting each person.

Having too many people to support at once leads to burnout and to Care Managers quitting.



Recommendations

The report recommends that:

Care Management Services

CCOs develop a training about OPWDD’s system that explains eligibility and availability of services, how to get services and how to make sure people are able to use them.

67

The report makes 67 recommendations about how to make things better.

A list of programs and services should be available to everyone online.

The process of moving from school aged services into adult services should start earlier, be explained clearly, and employment should be offered as a first choice.

Teams should be formed to help students move from school aged services into adult services.

Learning opportunities and training materials should be provided for Care Managers and other service providers to help them support people with complex or multi-system needs.

Self-advocacy, decision-making and self-care training should be available to youth.

The roles and responsibilities of Care Coordination Organizations, Care Managers, service providers, and others, as well as the process for getting service approvals should be defined in plain language and shared in a clear way.

26

26 recommendations are ways that OPWDD can make things better.

OPWDD should continue to provide workshops, meetings and online discussion groups to share updates.

OPWDD should create template messages that can be used by Care Managers to help explain why approvals are denied.

OPWDD should build an online system that provides automatic reminders.

Person-Centered Planning

OPWDD should create a Task Force of Care Coordination Organizations, Care Managers and OPWDD staff to look at how Life Plans are created.

20

20 recommendations are ways that Care Coordination Organizations can make things better.

CCOs should have examples of good Life Plans available online for Care Managers to review.

Care Coordination Organizations should share best practices and lessons learned with each other.

OPWDD should set up a way for providers and Care Managers to resolve problems when a person's Life Plan is not working.

OPWDD should provide a way for Care Managers to give feedback to help make the process better.

Service Access

The report recommends that OPWDD give people more options for certified and non-certified housing and providers that can help people with complex needs.

CCOs should train Care Managers on housing programs and resources available through local, state and federal government sources.

OPWDD, Care Coordination Organizations and service providers should work together to find gaps in services.

User-friendly tools should be created to help make connecting people with services easier.

17

17 recommendations are ways that OPWDD and Care Coordination Organizations can work together to make things better.

An online secure portal should be created between OPWDD and Care Coordination Organizations for timely information sharing.

Regular surveys should be done to collect feedback on challenges people are facing getting services or getting answers from Care Managers.

Roundtable discussions should take place between OPWDD, Care Coordination Organizations, hospitals, dentists and other healthcare or clinical service providers.



OPWDD should help Care Coordination Organizations to reach agreements with healthcare providers for access to Electronic Healthcare Records.

CCOs should have a contact person (“Communication Liaison”) to provide updates and answer questions from people who get services, families, and providers.

CCOs should also require that people’s questions are answered as soon as possible and by a certain deadline.

Social Activities

Care Coordination Organizations should develop an online platform with current information on programs and services for Care Managers.

Care Coordination Organizations should work with community clubs and centers, and cultural organizations to offer free or discounted access to people.

Care Coordination Organizations should help Care Managers make connections with local businesses to help people with developmental disabilities get jobs.



Care Coordination Organizations should hire people that help people with developmental disabilities find jobs.

OPWDD and Care Coordination Organizations should work together and create a plan to help people be more social depending on their age group and their goals.

Work Challenges

Care Coordination Organizations should give Care Managers tools and training to help do their jobs better.

Care Coordination Organizations should hire more staff to help with tasks like paperwork and reporting.

OPWDD should provide Care Coordination Organizations with a timeline for planned updates.

OPWDD should provide mandatory training for Care Managers about guidance updates.

OPWDD should provide online plain language manuals that are updated in real-time as guidance or regulations change so Care Managers have access to the most current information.

OPWDD should tell providers the maximum number of people that each Care Manager should be helping, based on each person's level of need.

OPWDD and Care Coordination Organizations should recognize staff for their good work to help staff want to keep doing the work they are doing.

OPWDD should do mandatory trainings on Diversity, Equity and Inclusion related subjects.

OPWDD and Care Coordination Organizations should provide language access classes in commonly spoken languages and should provide language access services, translation and interpretation to anyone who needs it.

Understanding the Service System

OPWDD should provide more time to Care Managers to get used to program changes.

OPWDD and Care Coordination Organizations should support Care Managers to take part in peer learning groups.



OPWDD with help from Care Managers and Care Coordination Organizations should create training that explains Care Management.

Care Coordination Organizations should work with healthcare and behavioral health providers to help with decisions.

Conclusions

The review found some things about the program are being done right and some things need work.

The review reports that the longer people use Care Coordination Organizations, the more they use Home and Community Based Services.

The review also reported that people and their families want more respite services, or a break from caregiving, but that can be hard to get because of low staffing.

The report notes that people are not going to the emergency room or hospital as much and when they do go, they are there for a shorter length of time.

Care Coordination Organizations also help people to be more active and social.

The review found that most people who receive OPWDD services are happy with their CCO, their Care Manager and their Life Plan and say that this service makes them healthier and safer and able to reach their goals.

However, some family members do not think the CCO process works well and would like to hear from their Care Manager more.

Most people think that person-centered services are a very important part of care management.

People are concerned about not having staff to help them and the amount of paperwork that Care Managers have to do.

Providers think that Care Managers need to do better at helping people get healthcare from a doctor or a dentist.

Overall, the review found that there should be better training and more communications between CCOs, Care Managers and providers.



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