



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

COORDINATION OF CARE FOR PERSONS WITH DISABILITIES ENROLLED IN MEDICAID MANAGED CARE:

A CONCEPTUAL FRAMEWORK TO GUIDE THE DEVELOPMENT OF MEASURES

December 2000

Office of the Assistant Secretary for Planning and Evaluation

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A Conceptual Framework to Guide the
Development of Measures**

Shoshanna Sofaer, Dr.P.H.
Barbara Kreling
Martha Carmel, M.S.P.H.

Baruch College School of Public Affairs

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TABLE OF CONTENTS

I. INTRODUCTION	1
A. Goal Of The Project: Develop Measures Of Care Coordination.....	1
B. Why Develop A Conceptual Framework?.....	1
C. The Document.....	2
II. WHOSE CARE NEEDS TO BE COORDINATED?	4
A. What Are The Potential “Inclusion” Criteria For Those Whose Care Needs To Be Coordinated?	5
B. What Are The Potential “Exclusion” Criteria For Those Whose Care Needs To Be Coordinated?	8
III. WHAT IS THE RELATIONSHIP OF CARE COORDINATION TO OTHER CONCEPTS?	11
A. Care Coordination And Coordination	11
B. Care Coordination And Case Management Or Care Planning.....	12
C. Care Coordination And Care Coordinators.....	15
D. Care Coordination And Continuity Of Care	15
E. Care Coordination And Utilization Management	16
F. Care Coordination And Disease Management Or Clinical Care Management	17
G. Care Coordination And Structural Integration Of Services	18
IV. WHAT LONG-TERM OUTCOMES DO WE HOPE TO ACHIEVE BY MEASURING AND IMPROVING CARE COORDINATION?	20
V. WHAT INTERMEDIATE OUTCOMES DO WE HOPE TO ACHIEVE BY MEASURING AND IMPROVING CARE COORDINATION?	22
VI. WHAT PROCESSES/ACTIVITIES ARE INCLUDED IN CARE COORDINATION?	24
VII. WHAT ORGANIZATION/STRUCTURAL FACTORS APPEAR CRITICAL TO EFFECTIVE AND EFFICIENT CARE COORDINATION?	26
VIII. WHAT STRUCTURES ARE NECESSARY TO SUPPORT THE CONSISTENT AND HIGH QUALITY IMPLEMENTATION OF CARE COORDINATION PROCESSES AND TO ACHIEVE INTERMEDIATE OUTCOMES?	27
IX. CONCLUSIONS AND NEXT STEPS	29
REFERENCES	30

I. INTRODUCTION

A. Goal Of The Project: Develop Measures Of Care Coordination

The purpose of this document is to present a conceptual framework to guide the development of measures of care coordination that would be both feasible to apply and meaningful in assessing the performance of Medicaid managed care organizations (MCOs) that enroll people with disabilities. Although there are no explicitly required care coordination systems now in place, some states are providing systems of coordination and doing it with existing resources. This document presents a structure for defining and measuring good care coordination for states that have systems and want to measure them, and for those who may wish to implement systems in the future.

This measurement development attempt has grown from a recognition, across stakeholders, that care coordination is one of the most critical dimensions of health care system performance for persons with disabilities; and that the full range of feasible and meaningful measures of this dimension are currently unavailable.

In response, the Office of Disability, Aging and Long-Term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) within the U.S. Department of Health and Human Services, and the Center for Health Care Strategies (CHCS), have jointly contracted with researchers at the School of Public Affairs, Baruch College, to develop such measures.

B. Why Develop A Conceptual Framework?

Researchers and funders agreed that an important step prior to developing specific measures would be to develop a conceptual framework of care coordination, with particular relevance to people with disabilities. We believe, indeed, that such a framework to define care coordination may be relevant to other groups as well, such as people with chronic conditions. But why is such a framework needed in the first place?

The primary reason is that there is little clarity or consensus about the meaning of the term “care coordination.” Like many terms in health care, it is defined in different ways by different people. In addition, other terms are often used that appear to be close in meaning to “care coordination,” but the extent or degree of overlap in the meaning of these terms is also unclear (Shortell 1976; Fletcher, O'Malley, Fletcher, et al. 1984; Siegel and Habel 1996; Chen, Brown, Archibald, et al. 2000).

Social scientists believe it is impossible or at least misguided to try to measure something that cannot be clearly defined. Typically, they distinguish, in the measurement development process, two phases: conceptualization and

operationalization¹ (Shortell 1976). This framework is part of the conceptualization phase. Operationalization involves the detailed specification of the actions (operations) needed to measure a concept in a valid and reliable manner.

In reviewing the literature in care coordination, we have come across many calls for clear conceptualization of this and related concepts (Sofaer 1998; Corrigan, personal communication; Martin, personal communication; Rosenbach 2000). For example, in the 1960s and 1970s much attention was paid to developing measures of “continuity” of care (see discussion below). Fairly quickly, participants in this process became frustrated at how many different definitions were being used for this term, and concluded that the lack of clarity and consensus about the concept of continuity was hampering measurement efforts and, in particular, making it difficult to interpret and assess the validity of research studies that often came to quite different conclusions. Policy makers, health plans, clinicians, as well as people with disability, need to be clear, when they look at data about care coordination, what it really is, and really is not, showing them about MCO performance.

C. The Document

This document is a conceptual framework. It is based upon extensive review of the literature as well as interviews with dozens of experts in measurement of health care quality and health care information systems, clinicians who serve people with disabilities, and people who have studied related fields such as continuity of care, case management and disease management. It is also based on the review of existing projects such as that developed and implemented by the State of Oregon in contracting with Medicaid MCOs.

We begin by discussing the target population for the measurement of care coordination: Whose care needs to be coordinated (Curtis 1999; Gill 1999)? We then move to a discussion of the relationship of the concept of care coordination to related concepts, including coordination in general; case management or care planning; care coordinators; continuity of care; utilization management; disease management or clinical care management; and the structural integration of services. The next sections of the document present the basic conceptual framework, which borrows from the classic distinctions of Donabedian (1980) regarding health care quality: structure, process and outcomes. We “work backwards,” beginning with expected long-term outcomes of effective care coordination; moving to intermediate outcomes; going next to processes and activities as well as key factors that will influence the effectiveness of process implementation; and finally specifying structures and other resources that will support and facilitate the implementation of process.

¹ Keep in mind that this is of concern to social scientists, in particular, because they are typically not measuring the characteristics of objects and readily observable events (such as the height of a table or how rapidly an apple falls from a tree), but rather abstract concepts (such as personal autonomy or health care quality).

As we have gone through this process, we have found it essential to keep in mind that care coordination is just one dimension of quality. Even the best coordinated care will not serve the needs of people with disabilities and their families, if other important dimensions of quality are not in place, and if resources are not available to make needed medical and related social services available. To some extent, a critical aspect of our task is to set realistic boundaries around the concept of care coordination for purposes of measurement, and to reflect realistic expectations of what care coordination, itself, can and cannot achieve.

II. WHOSE CARE NEEDS TO BE COORDINATED?

In an ideal health care delivery system, the care of all patients (indeed of everyone in the nation) would be coordinated. This would happen because the system was structured, financed and operated to achieve coordination as a matter of course, for everyone.² We do not have an ideal health care delivery system today, and we are unlikely to achieve such a system in the short or mid-term. Today's system is fragmented organizationally, financially, technologically, and in terms of the approach taken by various clinicians in providing medical care and linking it to other health and social services in the community. This project, therefore, focuses on care coordination for a specific group of people, those with disabilities, who are viewed as especially vulnerable to problems that arise when care is uncoordinated. We operate, therefore, in a context in which, whether we like it or not, care coordination will have to compensate for and overcome, wherever possible, the fundamental dysfunction of today's fragmented health care system. At the same time, however, we hope that our work will move toward, though it cannot fully achieve, the institutionalization of structures, processes, and commitments to outcomes that will enhance care coordination for all of us (Siegel 1996; Committee on Children with Disabilities 1999; Ronder 1999).

Since we are working toward measures for a specific population, we need to specify the "denominator," those whose care coordination are our primary concern at this time. Legal definitions will be problematic. For instance, the Balanced Budget Act (BBA) definition of Children With Special Health Care Needs is:

- receive SSI;
- eligible under 1902(e)(3)2;
- in foster care; receiving foster care or adoption assistance (Title IV-payments); or
- receiving Title V-funded care coordination services.

Problems with the BBA definition are that it misses children who qualify for Medicaid a different way, and that it cannot be used for a count because the five groups overlap. States interviewed for a NASSHP study (Colorado, Connecticut, Delaware, Massachusetts, Minnesota and New Mexico) reported it was more important for them to identify children in a way that allowed them to be engaged and tracked. In addition, states reported that they can identify children in all groups but Title V-funded care, because no system exists for communicating individual-level information from the Title V agency to the Medicaid agency. Thus, since legal definitions are not adequate, we must identify both the "inclusion" and "exclusion" criteria in conceptual terms.

² The Institute of Medicine is embarked, as part of its effort "Quality of Health Care in America," on an attempt to specify the "chassis" needed to drive quality in the health care delivery system in the years to come. This chassis will attend to such broader issues as organization, financing, professional education, information system development, and the role of the patient/consumer. Given the participation of IOM staff on our Technical Advisory Group (TAG) and Technical Expert Panel (TEP), we hope to learn from their endeavors as we proceed.

A. What Are The Potential “Inclusion” Criteria For Those Whose Care Needs To Be Coordinated?

1. “Aid” Status--SSI Eligibility

The immediate need for this framework and measures is to assess the performance of MCOs that contract with state Medicaid agencies to provide covered health care services to people eligible for Medicaid under one or more categories. Quite naturally, our attention is drawn, in particular, to people who are eligible for Medicaid because they have a disability that meets the criteria for Supplemental Security Income (i.e., the SSI disabled) (Davis 1996). The primary advantage of using this as a primary inclusion criterion is that the records of state Medicaid agencies do identify persons by aid category, although this information is not always available to the MCO in which SSI disabled persons enroll.

There are two disadvantages of using this as a primary inclusion criterion. First, it is likely that some people eligible for Medicaid under other aid categories also have disabilities. This includes adults and especially children enrolled under Temporary Assistance to Needy Families (TANF) and frail elders who “spend-down” and become dually eligible for Medicare and Medicaid (Moore, personal communication). Second, it is not clear that all persons with disabilities need care coordination services. For example, an adult with a sensory impairment such as blindness or deafness may be in quite good health and, furthermore, be both able and willing to take responsibility for whatever care coordination needs they have (Goldberg, personal communication).³

Although for purposes of immediate practical application of measures, the criterion of eligibility as an SSI disabled person may have to be used, by itself or in combination with other criteria. However, persons receiving SSI, those receiving Medicare, and those eligible for both Medicare and Medicaid, are different populations with different demographics. For instance, if we examine a profile of persons with disabilities receiving SSI (HCFA Review 1996, Volume 17, Number 4) we find that the primary disabilities for both children and adults are mental impairments (including mental illness, mental retardation, and developmental disabilities). These account for 57 percent of adults and 67 percent of children. Diseases of the nervous system and sense organs account for 13 percent of children and 25 percent of adults; diseases of the musculo- skeletal system account for 32 percent of adults and congenital abnormalities and respiratory diseases account for 8 percent of children. Ages of the SSI disabled population are as follows: of total SSI recipients, children less than 18 years old were 22 percent, adults 18-49 years old were 51 percent, and adults 50-64 years old were 26 percent.

³ They are, of course, likely to need accommodations from the health care delivery system in order to make effective use of its resources, but that is not the same thing as care coordination.

In most states, those who are receiving SSI payments are automatically enrolled in Medicaid. States vary, however, in the extent to which they are enrolling their disabled populations in managed care for their acute care services. While we have extensive information about the characteristics of Medicare disabled, and those enrolled in managed care, we have less information about the disabled receiving Medicaid. We do know that the demographics of these two groups are different. For instance, the 41 percent of disabled Medicare recipients who are also eligible for Medicaid are more likely to have mental impairments and very low incomes.

Given the disadvantages we have noted in using SSI determination, we will discuss below the advantages and disadvantages of alternative, or additional criteria. A major disadvantage of all these proposed criteria is that they would require primary data collection efforts to identify, within an enrolled population, those who meet one or more criteria. A major advantage is that care coordination would be more carefully targeted to a population most likely to need and benefit from it, and that scores on performance measures would be more specific and sensitive, and therefore easier to interpret. For instance, mild to moderate disabilities may not fit SSI criteria for disability, but may require care coordination.

2. Functional Status as Indicated by ADL's and/or IADL's

A frequent suggestion in the literature, particularly in work that discusses the needs of the frail elderly, is that care coordination should be targeted at people who have limited functioning, and who are therefore both in need of a mix of medical and non-medical services and at risk, if they do not receive such services, of functional decline and long-term institutionalization. Care coordination (typically called case management or care management) has been a recurring element of attempts to provide home and community-based services as an alternative to institutionalization of the frail elderly (Eng 1997). Eligibility for such programs (and indeed for some aid categories) has been based upon the measurement of functional status as indicated by limits in the person's ability to perform the basic Activities of Daily Living (e.g., bathing, dressing, ambulating, transferring, eating) and/or Instrumental Activities of Daily Living (e.g., shopping, cooking, balancing a checkbook) (Pawlson, personal communication).

Instruments to assess functional status are available (Bergner 1976; Katz 1983; Reuben 1999). While the early development of such instruments focused on older adults, some work has been done on adapting the concept of functional status to special needs children and other groups of people with disabilities (Harris 1983; Granger 1993; Keller 1999; Msall 1999). It is not clear, based on the literature, that measurement of functional status is sufficiently specific for targeting care coordination. A number of studies and researchers note that experiments in home and community-based services for the elderly and other groups at risk for institutionalization have often failed to be effective (especially cost-effective) because they have not been well targeted (Weissert 1998; Weissert, personal communication). However, if Medicaid enrollees in MCOs were screened for functional status, this would likely yield a lower "denominator" than the SSI disability criterion alone.

3. *The Nature and Extent of the Person's Service and Support Needs, Based on Their Medical, Psycho-Behavioral Socio-Economic Circumstances*

If we step back, for a moment, to examine why special care coordination efforts are important to an individual or group, given our current health care system, it is because:

- They have multiple needs that cannot be met by a single clinician or by a single clinical organization (even if it is highly integrated) (Coleman 1979; Jessop 1994; Master 1996; Leutz 1999); and/or
- These needs are ongoing and their mix and intensity may well change over time (Johnson 1988; Blum 1991).

Multiple Needs:

Many, though not all, people with disabilities are likely to need services from at least one clinical specialist, and may need multiple specialists, as well as a primary care provider (Ziring 1988; Meijer 1997; Mack, personal communication). For their health needs to be met, they may need special transportation services or require someone to accompany them to medical appointments. They may have behavioral health needs, either independent of or related to their disabling condition. They may need considerable educational support if they are to maximize their capacity for independent living and management of ongoing conditions. They may need durable medical equipment or other assistive devices. Their family and home environment may need attention in order to ensure that the person is safe, that their medical needs are taken care of, that adherence to medical regimen is feasible and likely, and to support autonomy. It is also essential to realize that clinical preventive services are needed by this population as well.

Ongoing and Dynamic Needs:

Most people with disabilities will have ongoing, in some cases life-long, needs for multiple services. However, these needs are not stable. It is not possible to do an initial assessment of needs, develop a plan to meet those needs and leave it at that. Many factors can result in changes in the mix or intensity of needs. These factors include changes in the underlying condition(s), normal development and aging, changes in the availability of technology, and changes in the life circumstances of the individual (Bulger, personal communication). For example, one or more of a person's health problems may be subject to periodic exacerbations that would require inpatient care at some level for some period of time. As a child with special care needs enters adolescence and young adulthood, their psycho-social needs (including needs for autonomy and responsibility) are quite likely to change, and their life circumstances and relationship to family may also change (Blum 1991). A new kind of assistive device may change what the person can do for themselves. Death or illness of a critical family

caregiver, or a sudden decline in family cohesion, may also require changes in what is provided, and how it is provided.

A number of proxies have been suggested in the literature to identify people with multiple needs from clinical or administrative data, such as records of visits to multiple clinicians or for multiple diagnoses, records of frequent emergency room visits, and the primary diagnosis and site of recent inpatient stays (Nerenz, personal communication). These proxies may be useful “stopgaps” especially if they are monitored over time, but may not provide a comprehensive list of people with care coordination needs. An alternative is to regularly screen health plan members, or a subset of members defined by aid category, both at initial enrollment and periodically thereafter (Curtis 1999; Ronder 1999). Several attempts have been made by MCOs and integrated delivery systems to carry out such screenings; on occasion individual MCOs have developed screening instruments for this purpose. In other cases, a standard health and functional status assessment instrument such as the SF-36 has been used. We have yet to identify a screening tool that is widely accepted and used, and that addresses not only medical but psycho-social and environmental issues. If functional status is viewed as an appropriate inclusion/exclusion criterion for measurement, we will pursue this further.

4. Potential for Anticipatory Intervention to Reduce Risk of Institutionalization or Functional Decline

We have stressed that care coordination involves interaction with a person over time (Van Achterberg 1996). Care coordination should, we believe, provide a different, less episodic, context for interactions with the health care system. In fact, in addition to responding to emergencies and crises, effective care coordination has the potential for being anticipatory (Sandstrom 1996). Assessments can focus not only on current status, but on likely future courses, and identify interventions that can reduce the likelihood of functional declines, exacerbations, and consequent use of emergency and institutional services. Ideally, given our desire to target care coordination to those most likely to benefit, we should attempt to assess the potential for anticipatory interventions. Unfortunately, however, instruments of this kind do not exist at this time.

B. What Are The Potential “Exclusion” Criteria For Those Whose Care Needs To Be Coordinated?

1. Member’s Needs for Medical Care, in Particular, are Not Significantly Different from the Average Person in Their Age and Gender Cohort

This and other exclusionary criteria are, to some extent, the “flip side” of our inclusionary criteria. Thus, we believe the denominator should, if possible, exclude some of the people with disabilities whose medical care needs, in particular, are fairly typical of people in their age and gender cohort (Jha, personal communication). However, such individuals may need accommodations to their conditions as well as assistive devices. It may be important to ensure that their primary care provider

understands and is comfortable working with a person with disabilities. If they need substantial coordination of non-medical needs such as needs for transportation, housing, special education or personal assistance (Henningesen, personal communication) this coordination may appropriately take place within a health care setting, especially since attention to these needs may prevent medical problems in the future. Indeed, it may be very important that the health care system be willing and able to coordinate with other human services systems (Weiss 1986).

2. Member's Condition is Stable and Expected to Remain Stable Over Time

Another indicator that the person may not need care coordination is that their disability or disabling condition is stable and expected to remain stable over time. Thus, the need for ongoing tracking and follow-up does not exist (Jha, personal communication). However, that a condition is stable for a period of time does not mean it will remain stable. The person and/or their family may need access to care coordination sometimes, such as in emergent situations.

3. Person and/or Family Prefers to Coordinate Medical Care and Related Social Services themselves and Appears Able to Handle Coordination Tasks Effectively

Independence and autonomy are highly valued by many people with disabilities and their families. Given the fragmentation of the health care delivery system, many have become genuine experts in how to coordinate medical and social services for themselves or their loved one. They may prefer to continue carrying out these tasks themselves, be confident of their ability to do so, and be able to document a "track record" to prove it. They may believe that their circumstances will be less fully understood and their preferences given less weight by a "professional" in care coordination (Wehmeyer 1993). So we must ask the question, should individuals with disabilities and their families be their own care coordinators (Ronder 1999)?

First, note that a significant subset of people who want to and can handle their own care coordination may meet one or both of the first two exclusion criteria we discuss. However, there are also going to be people with quite complex and dynamic needs who want at least to take the lead in the coordination of care for themselves or a family member. We would argue that even if the primary or lead responsibility for care coordination is not "in the system" but rather "in the patient" it may be important to include such individuals in the denominator for care coordination measures. We still need to ensure that the patient's needs are actually being met, especially if they change over time.

Further, we argue that people need access to formal care coordination and to periodical review of whether or not needs are being met and how rules/service changes and new resources affect their care. In addition, families and persons with disabilities may need formal care coordination in specific circumstances, such as when emergencies arise; when "burnout" is imminent; when the "system" poses active

barriers to patient and family initiatives that they cannot handle on their own; and when the circumstances of the family member or patient are affected by changes in health status, employment or other events. Finally, we believe it is important for the patient and family to know that back-up assistance from formal care coordination systems is available, in order to encourage them to play this role over time.

Thus, we incorporate into the concept of care coordination the notion that the preferences *and the resources* of the patient and/or the family need to be taken into consideration in the process of care coordination (see Section VI below) (Mack, personal communication; Moore, personal communication; Ziring, personal communication).

4. *Member Already has Access to a Coordinator of Services, Including but Not Limited to Medical Services, as a Consequence of Eligibility for Other Federal or State Programs*

Especially for children with special health care needs, other programs exist (e.g., maternal and child health programs, Individuals with Disabilities Education Amendments [IDEA], Title III of Ryan White) for which children eligible for Medicaid may also be eligible. These programs may assign a care coordinator for the children in their program. In some cases, the responsibilities of this care coordinator goes across systems of care. When this is the case, is it likely that the care coordination function in Medicaid managed care would be duplicative? Clearly, we do not want to reproduce a system in which clients have multiple care coordinators who then need to be coordinated. We also do not want a situation in which, because there are multiple care coordinators, no one takes real responsibility for assuring that care is in fact coordinated. The roles and boundaries in these circumstances will need to be carefully defined (Schneider 2000) so that someone is identified as overall coordinator.

III. WHAT IS THE RELATIONSHIP OF CARE COORDINATION TO OTHER CONCEPTS?

In this Section, we work toward definitional clarity by identifying both overlaps and boundaries between care coordination and other related concepts.

A. Care Coordination And Coordination

The literature in organizational theory and management is a valuable source of insights in defining care coordination. The classic theorists about organizations note that in creating an organizational structure and defining roles and responsibilities, organizations must both “differentiate” (or specialize) and “integrate” (or coordinate). This distinction makes it clear that the need for coordination of any kind is inevitable, growing as it does from the need to define individual and unit roles that are specialized. We specialize in order to become both more efficient (by standardizing) and more effective (by developing special expertise). Health care as a system is highly specialized; thus it is not surprising that the need for coordination is great, and that the task of coordination is difficult.

The work of Thompson (1967) includes an especially useful discussion of coordination in an organizational context. All organizations need coordination mechanisms to handle what he terms “interdependence” between individuals and units. The same framework could also be applied to interdependence between and among entire organizations. The kind of mechanism needed to handle interdependence depends on the demands of the technology that is employed by the organization.

Thompson defines three kinds of interdependence, each requiring different kinds of mechanisms that also vary in the intensity and kind of resources and effort they require. First is “pooled” interdependence, in which the organization can only produce its goods or services by pooling the contributions of multiple individuals or units. A secondary school is organized in this way: each teacher supplies part of the curriculum for each student. The method used to coordinate in these circumstances is “standardization,” in particular standardizing roles and procedures so the parts add up to the whole consistently. Second is “sequential” interdependence, in which a given individual or unit of an organization can only do its job if some other person or unit does their job correctly and in a timely manner beforehand. An example of this is a manufacturer with an assembly line. Thompson says the coordination mechanism here goes beyond standardization and into planning (including scheduling). The third type of interdependence is the most difficult to achieve, and requires the most communication and decision effort. It is “reciprocal” interdependence, and the only coordination mechanism that works in these circumstances is “mutual adjustment.” In this kind of interdependence, individuals and units need certain things from each other, including both information and the appropriate performance of assigned roles, in order to produce

a good or service efficiently and effectively. Notable examples of this kind of coordination are the launch of a space shuttle or a political campaign, which require timely information and adjustment.

All three kinds of interdependence are present in the delivery of health care services. We would argue, however, that reciprocal interdependence is particularly present in the delivery of services to people with disabilities. While care coordination should be designed to deal with pooled interdependence (e.g., identifying the several distinct services a person needs and making sure they get each one) and sequential interdependence (e.g., arranging and supporting transitions from hospital to home care), the most demanding tasks of care coordination involve reciprocal interdependence (e.g., making sure that changes in the home environment or the patient's condition that are identified by a visiting nurse are communicated to the primary care physician and other involved clinicians, so that adjustments can be made in prescribed medications and services).

B. Care Coordination And Case Management Or Care Planning

The term care coordination is often used interchangeably with the terms case management and care planning. Indeed, in many cases "care coordination" came to be used instead of "case management" because the latter term had negative connotations to patients. As one older gentleman told us in a focus group: "I am not a case and I don't want to be managed."

Case management has been used for decades to deal with specific target populations, including those who in the past might have been taken care of in institutions where "all" their needs were met (except, in many cases, needs for autonomy, dignity and individual development). When populations were either "de-institutionalized" as in the case of the chronically mentally ill, or "at risk for institutionalization" as in the case of frail elders, case management was used as a central part of interventions designed to patch together services that could take the place of those present in "total institutions" (Itagliata 1982; Bachrach 1993).

Over time, a set of specific functions became associated with case management or care planning, as it is sometimes called. These classic functions include:

- Assessing the full spectrum of client needs;
- Developing a treatment plan to meet those needs and specifying who would provide which plan elements to the client;
- Arranging for services in the plan to be provided (and in some cases paid for);
- Following up to ensure that services were in fact delivered and having the desired consequences; and
- Periodically re-assessing needs and adjusting treatment plans accordingly (Kane 1987, Schwartz 1982).

Note that there is no explicit use of the term “coordination” in this set of functions. If we use Thompson’s three types of interdependence, it would appear that case management is primarily dealing with “pooled” and “sequential” interdependence, rather than the more difficult “reciprocal” interdependence. In practice, however, many case managers do address the problems that arise when those providing services to a client are in fact reciprocally independent but may not recognize that fact and/or may fail to make the required “mutual adjustments.” It is not clear that case managers anticipate these interdependencies and create or support mechanisms to deal with them (Siegel 1996). In many cases, they may not have the resources, skills, or “clout” to do so. We would argue that care coordination, to be effective, must.

We and others have argued that case management is a response to a broken and fragmented system, and that it has seldom been used to support system-level changes, but rather has been used to help individual clients navigate the shoals of turbulent health care systems (Evashwick 1996; Sofaer 1994). As we have already noted, given the fragmented nature of health care today, it is likely that care coordination, too, will be required to find individualized “fixes” for specific people, because they cannot wait for long-term changes to be defined and implemented. At the same time, it would appear wasteful to ignore the learning that can be achieved when the experiences of multiple clients with system-level problems are aggregated and analyzed to identify patterns as well as opportunities for improvements. We therefore include, among the processes and activities included in care coordination (see Section VI below), participating in the process of identifying persistent system problems that impede care for people with disabilities (Schwartz 1982).

While the case management functions we have described above are generally common, many other aspects of case management vary in consequential ways. These include:

- The disciplinary base and level of education/training of the case manager (for example, case managers for the chronically mentally ill vary from paraprofessionals through nurses and social workers to psychiatrists);
- Whether or not the case manager is also providing direct clinical or other services to the client;
- How much control or influence the case manager has over resources needed to access or purchase services;
- The caseload size and mix of the case manager;
- Whether s/he works only on services provided within a single agency or actually manages services provided by multiple agencies; and
- A related issue, the range of services (i.e., medical and social, medical only, social only) that are being “managed” (Itagliata 1982; Kanter 1989).

While there are many opinions expressed in the literature about the “correct” approach on each of these dimensions, there is little solid empirical evidence to identify an approach that will always be the “correct” one. For the most part, therefore, we will

try to avoid being either “prescriptive” or “proscriptive” as we move toward the development of measures. However, given that Medicaid managed care depends on the effectiveness of its contracts with MCOs, it is essential that in this area as in many others, contract specifications must be clear in order for MCOs to be held accountable for their performance (Rosenbaum 1998). Contract specifications, and measures, must and will reflect priorities and value judgments as well as empirical evidence.

For example, the last “bullet” relates to an issue that is both important and remains unsettled: should our measures speak to the coordination only of those medical services that are specifically covered, for example, in state Medicaid agency contracts with MCOs? Or should they also speak to the coordination of related social and human services (Rudolph 1993)? This gets at the issue of “what care is being coordinated?”. In our discussions with our TAG consensus could not be reached on this issue. Medicaid state agencies believed that this responsibility for this kind of cross-sectoral coordination could not be paid for, therefore could not be “required” in contracts, and therefore could not be incorporated into a performance measure. On the other hand, virtually all our stakeholder advisers and our TEP agreed that somehow this kind of coordination had to take place, if the care of people with disabilities was to be truly “coordinated.”

Leutz (1999) makes a useful distinction in discussing the coordination of acute and long-term care services, which can be viewed as highly related to coordination of medical and related social and human services. He and colleagues distinguish between systems that attempt full integration (see our discussion of structural integration below), coordination, and linkage. We suggest here that Medicaid MCOs *do* need to be held explicitly accountable for *coordinating covered services*; but that they should also be held accountable for *creating linkages* with those providing other related services. One potential problem here is that, in some cases, behavioral health services have been explicitly “carved out” from Medicaid managed care programs (Regenstein 2000). Given the high incidence of people with serious cognitive impairments and chronic mental illnesses within the group of people with disabilities, this may be such a fundamental problem for care coordination that it requires special attention, not only by the MCO but by the state Medicaid agency itself.

Other authors (e.g., Rosenbach 1999) note that in many cases, other systems are resistant to working with the health care system. Some believe that the state Medicaid agency needs to take responsibility for convening and encouraging more positive interactions with other relevant state agencies (e.g., education, housing, foster care, mental health, developmental disability, services for the aging) as part of a move to explicitly incorporate people with disabilities (in particular, the SSI disabled) into managed care, especially mandatory managed care.

C. Care Coordination And Care Coordinators

The simplest way to measure care coordination, but by no means the most appropriate, would be to simply ask and answer the question “Does the MCO have care coordinators that are assigned to members with disabilities?”. Indeed, a frequent “knee-jerk” reaction to a need for care coordination is to hire or identify people as care coordinators. Many assume, for example, that care coordination is a distinct service, provided by care coordinators. While this may be true, we would argue that while the identification of appropriately educated and trained individuals as “care coordinators” is (at least now) *necessary* to achieve care coordination, it is by no means *sufficient* (Donaldson, personal communication). The need for care coordinators is reflected in how many people with disabilities, their family members, and their clinicians, point to the great need for “a single person” who can be, at a minimum, a central point of contact especially, but not exclusively, in times of crisis, and who can amass, over time, a very detailed and nuanced understanding of the particular individual and their home and community context. This “single person,” it is stressed, must have a similar intimate knowledge of the MCO itself and of resources in the community beyond the MCO (Bennett 1997; Cocotas, personal communication; Goldberg, personal communication).

But for care to be coordinated efficiently as well as effectively, a care coordinator is not enough. At the organizational level, mission and commitments, relationships with external entities, information systems, financial arrangements, and relationships with providers will all make a difference (Goldberg, personal communication; Sofaer 1994). At the provider level, understanding of persons with disabilities, recognition and appreciation of the role of care coordination, willingness and ability to share information, all will make a difference. So the definition and, ultimately the measurement of care coordination, must go substantially beyond the mere presence of care coordinators (Leutz, personal communication).

D. Care Coordination And Continuity Of Care

In discussions with our TAG, we raised the issue of the relationship of care coordination and continuity of care, which has been a concern within medicine, and especially primary care, for several decades. They agreed that continuity of care was a part of care coordination, specifically coordination of care received over time, but that coordination was a broader and more complex concept.

Continuity, and related terms such as “longitudinality” has been defined and measured in a number of ways over time. Our work in this area has been immeasurably enhanced by access to the research and thinking of Molla Donaldson, who provided us with her thoughtful analysis and synthesis of the research on continuity (personal communication). Continuity appears to have been of particular interest with respect to care provided by physicians. It has often been defined as the use of the same clinician over time, or in a related way by the existence of a “usual source of care” whether that

was a particular individual or a group practice setting such as a community clinic (Bass 1972; Hennen 1975).

Over time, however, the concept had to be broadened to address such issues as referrals to specialists, and whether the primary care physician knew about the use of specialists and got information about the insights of specialists and the treatments they prescribed. The emergence of multi-disciplinary teams made the concept of continuity of a single provider less meaningful. In the population of the frail elderly, in particular, transitions from one care setting to another and the appropriate specification of “level of care” within the “continuum” also make it difficult to stay with a narrow definition of continuity. As we enter the 21st Century, the emergence of the “hospitalist” physician poses another challenge to individual clinician continuity as a concept and as a “norm.” Indeed, the literature, fairly early, began to use the word “coordination” in defining continuity (Starfield 1976).

It may indeed be the case that continuity of provider(s) be one but not the only approach to supporting care coordination. It may be an especially significant element of care coordination for certain people with disabilities (for example, those with rare diseases or those who have developed a uniquely satisfying relationship with one or more providers or settings). But continuity of provider does not guarantee coordination, and coordination may occur in situations where provider continuity is far from perfect (Addington-Hall 1992).

E. Care Coordination And Utilization Management

One reason that the term “case management” has a negative connotation to some is that it has become associated not with ensuring that people get what they need, but rather to ensuring that they get ONLY what is absolutely essential. Indeed, some insurers and employers began to implement “high cost case management” programs specifically to reduce utilization and costs associated with complex and difficult cases (Alexandre 1990). Sometimes these programs recognized that early interventions and the delivery of non-traditional (read social) services could both reduce costs and improve health, functioning and even autonomy. All too often, however, they were no more than especially aggressive utilization review and management activities.

The relationship of care coordination and utilization management is important. Many on the panel feel that in order for care coordinators to be effective, they need the ability to authorize services and, likewise, the responsibility for allocating services. Conceptually, though, it is clear that care coordination and utilization management are not, and should not be the same thing. In practice, they have to interact. Some have argued, for example, that care coordination functions should be organizationally separate, within the MCO, from utilization management, but have often also argued that care coordinators need to be able to influence the decisions of those doing utilization management, to make sure that they do not interfere with access to services in the treatment plan. Some recommend that the services specified in a treatment plan be

automatically considered as “authorized” in advance, thus side-stepping utilization management most if not all the time. Others have argued that care coordination should have to face the discipline of limited resources, so that they target resources more precisely. They often suggest that a kind of “global budget” be available for a group of patients, and that specified kinds of care be provided (or purchased) from this single pool of resources (Zelman 1998).

F. Care Coordination And Disease Management Or Clinical Care Management

One approach to measuring the coordination of care is on a condition or disease-specific basis. Our TAG agreed that in this project, we should be working toward generic, rather than disease-specific measures of care coordination, especially because the population of people with disabilities in a given MCO is typically so small to slice it up by disease category would make a reliable and valid measurement impossible⁴ (Corrigan, personal communication).

Nevertheless, it is important to note that, in tandem with the growth of the evidence base about the management of common chronic illnesses. In particular, disease management protocols are becoming more common and more commonly used, especially by MCOs. Such protocols provide guidance about specific events and behaviors which should occur, when they should occur, and often also specify how information should flow. Thus, disease management protocols are like standardized treatment plans, and tracking their implementation would be similar to following up to assure that plans are followed. While useful, standard protocols may also be problematic for the population of people with disabilities, since they rarely:

- Address the needs of people with multiple conditions.
- Take individual variation, even in a single condition, into account.
- Provide a meaningful role for the patient and/or their family.⁵

Where appropriate protocols exist, or when they are developed, for certain disabling conditions, it is likely that they will be important resources for MCOs, clinicians and for care coordination. However, at this point in time we are not conceptualizing care coordination as a version of disease management (Woolf 1991; Shaneyfelt 1999).

Perhaps a more critical issue is the relationship of care coordination to clinical care management more generally. The subgroup on care coordination organized by the Center for Health Care Strategies (CHCS), in identifying ten important elements of care

⁴ The exception the TAG made was that some measures may be relevant specifically to children.

⁵ An important exception are protocols built around the concept of "patient self-management" of chronic conditions, such as those developed and used at the Group Health Cooperative of Puget Sound.

coordination, specifically distinguished it from clinical care management (Rosenbach 2000). That could seem to imply that something other than clinical care is being managed and further that the person's primary clinician should not be responsible for coordinating their care.

We would argue that the care provided by clinicians is part, though clearly not all, of what should be coordinated. This means that clinical care management is related to care coordination, but that care coordination includes more than clinical management (Desguin 1994; AAP). Further, we would argue that few physicians, whether generalists or specialists, are in a position to coordinate all the care of identified patients with disabilities, given the time constraints under which they operate, as well as their lack of knowledge and training. Staff affiliated with physicians' offices (especially group practices) may be far more appropriate in this role, if and only if, they are willing to conceptualize the job of care coordination as addressing needs that cannot be met by the physicians and other clinicians in the particular practice.

G. Care Coordination And Structural Integration Of Services

The classic "staff model" Health Maintenance Organization (HMO) can be viewed as an attempt to provide structural support for the coordination of care for enrolled members. Indeed, managed care leaders from such HMOs believe that they are uniquely well positioned to provide coordinated and more effective care to people with chronic conditions and disabilities. The idea here is to pull together, in a single organizational structure, all the professionals and services needed to provide health care to a defined population of enrollees. This is sometimes referred to, in the health care management literature, as "vertical integration"(Devers 1994).

In fact, using structural means to achieve coordination has a long history. This author was involved, during the War on Poverty, with efforts to create "multi-purpose neighborhood centers" that would integrate in one physical location, and under the governance of a single community-based board, a full range of human services needed to help people move out of poverty. The Model Cities program included similar efforts. Today, building on the expanded capabilities of information and communication technologies, attempts have focussed on a more "virtual" structural integration, related to the concept of "one-stop shopping." In this approach, a client can access a full range of services no matter where they enter the "virtually integrated" system, because of carefully designed flows of information regarding eligibility, appointment schedules, etc.

In today's health care world, most HMOs are moving away from tightly organized staff models, making it more difficult to use structural features to support care coordination. At the same time, however, provider systems have been and are being developed in which a continuum of services are structurally integrated (including

through the use of information systems), even though the providers may contract with multiple MCOs. We cannot depend upon the existence of structurally integrated systems. On the other hand, there may be elements of such systems that are of particular importance in supporting care coordination. These are discussed in Section VII below.

IV. WHAT *LONG-TERM* OUTCOMES DO WE HOPE TO ACHIEVE BY MEASURING AND IMPROVING CARE COORDINATION?

Review of the literature indicates that the following are the long-term outcomes that are expected to be influenced by effective and efficient care coordination (Devers 1995; Seigel 1996; Van Acterberg 1996; Bennett 1997; Watson 1997; Hughes 1999; Ronder 1999; Brede, personal communication; Bulger, personal communication; Jha, personal communication):

- Improve patient experience;
- Improve family experience;
- Decrease family caregiving burden;
- Improve provider experience,⁶
- Maintain or improve functional status, independence and community participation;
- Maintain or improve health status; and
- Prevent secondary complications.

Some authors argue that effective care coordination should also reduce the costs of caring for people with disabilities (Master 1996). However, it is clear that savings accrue over the long-term, and may be experienced by organizations other than a given MCO, the state Medicaid agency, or even more broadly the public. For instance, long-term external outcomes may lead to less divorce. At the same time, investments both in measurement and improvement of care coordination are required up-front. It may be unrealistic to expect that care coordination will create savings in the short and mid-term, especially for the organizations that pay for the coordination. Furthermore, building in such expectations at the outset may distort both the design of care coordination efforts and their measurement (Stuart 1998).

It is important to note that the outcomes specified above are also “dependent variables” of other interventions to improve quality of care, and that if other quality dimensions are poor, even the best efforts of those coordinating care may fail to have these desired outcomes. We therefore believe that it will be important to further specify the particular aspects of patient experience, family experience, provider experience, functional status and participation that can be attributed with greater confidence to care coordination itself. For example, patient, family and provider experience with particular elements of care coordination can be specified through items in surveys (Pawlson, personal communication). We believe it will be difficult to come up with a measure of health or even functional status that will be valid, even if used with a cohort of people

⁶ Provider experience may decrease with more coordination. Especially for physicians. It may create more work to communicate with others about things they may not know much about.

over time, as an indicator of MCO performance in care coordination (see our earlier Resource Guide [Sofaer 1998] for a discussion of the limitations of such outcome measures as performance indicators). While efforts may need to be made to measure and track health and functional status (perhaps for all or a significant sample of Medicaid managed care enrollees), it will be hard to attribute variations across MCOs or over time with accuracy.

V. WHAT *INTERMEDIATE* OUTCOMES DO WE HOPE TO ACHIEVE BY MEASURING AND IMPROVING CARE COORDINATION?

Given the limitations of long-term outcomes as performance measures of care coordination in particular, it is especially important to focus on intermediate outcomes, in order to clarify our expectations regarding care coordination, indicate the causal “pathways” we assume in moving toward longer term outcomes, and give direction to practical measurement efforts. We have identified the following list of intermediate outcomes, which may not be exhaustive (Starfield 1976; Italgliata 1982; Bachrach 1993; Wehmeyer 1993; Kerbergen 1996, Moore, personal communication; McTaggart, personal communication):

1. Increased patient and family participation in maintenance and improvement of their own health. For example:
 - health-related behaviors move in the right direction;
 - adherence to treatment regimens increases;
 - missed visits and failed follow-up of referrals by patients decline;
 - patient and family self-advocacy increases.
2. Patients receive all medical care services specified in their treatment plan.
3. Patients receive services in the least restrictive medically appropriate setting.
4. Delays in the receipt of services (especially services needed in crisis situations) are reduced or eliminated.
5. All providers caring for a particular patient have current information about the health and functioning of the patient, critical life events, services being provided and the patient’s response to the services.
6. Prescriptions for and delivery of treatments (including medications) that are inappropriate given other conditions and treatments being received by the patient are reduced or eliminated.
7. Duplication of services is reduced or eliminated.
8. Preventable use of costly services (e.g., emergency room visits, hospitalizations, nursing home placements, services for preventable complications and sequelae) is reduced or eliminated.

9. Negative medical and psycho-social sequelae of transitions from one care setting to another are reduced.
10. Complaints, grievances and incidence reports for this population are reduced.

VI. WHAT PROCESSES/ACTIVITIES ARE INCLUDED IN CARE COORDINATION?

What processes and activities are needed to achieve these intermediate and long-term outcomes? Based on the literature and our discussions with experts, we have identified the following list:

1. Outreach and identification of individuals in need of care coordination (Leutz, personal communication).
2. Assessment of the current health, functional and psycho-social status of the patient and family (Bulger, personal communication).
3. Assessment of the home and community context of the patient and family (Mack, personal communication).
4. Identification, with patient and family, of their health and functioning goals and their preferences with respect to receipt of services (Brede, personal communication).
5. Identification, with patient and family, of the resources and assets they bring to achieving goals (Mack, personal communication).
6. Education of the patient and family of the resources and services which are, and are not available within the MCO and in the community (Leutz, personal communication).
 - This would include providing information regarding the rules and procedures of the MCO with respect to accessing services, appealing denials of service, and making complaints grievances.
7. Specification (in collaboration with the patient and/or family) of service needs (current and likely short and mid-term future), including medical care services, enabling and support services provided by the MCO and related social and educational services that could be provided by other agencies and individuals (Leutz, personal communication; Ziring, personal communication).
8. Articulation of a plan for accessing these services, within and outside the MCO (Bulger, personal communication).
 - Note that some elements of the plan may be carried out by the patient and/or family.
9. Developing the plan in writing and delivering it to the patient and/or family (Moore, personal communication).

10. Arranging for the receipt of these services, in a manner as close as possible to the preferences of the patient and/or family.
11. Facilitating ongoing communication between care coordination staff, clinical providers and administrative staff of the MCO regarding patient status, progress, concerns and response (Jha, personal communication).
12. Following up to determine if services are provided and if patient and/or family carries out elements of the plan for which they are responsible.
13. Documenting the delivery of services provided (MacTaggart, personal communication).
14. Where necessary, advocating for the patient and/or family in accessing needed services in a preferred manner; resolving problems experienced by patients and providers (Leutz 1999).
15. Addressing unexpected problems and providing support during crises (Anderson 1996; Patrick, personal communication).
16. Conducting regular re-assessments of goals, preferences, resources and service needs; adjusting treatment plans accordingly (McManus 1996).
17. Supporting transitions of patients across providers, facilities, and when necessary MCOs, over time (for example, through the maintenance and with appropriate permission transmission of records) (Devers, personal communication).
18. Serving as a source of information about persistent problems at the systems level which impede efficient and effective coordination of care for people with disabilities (Ziring, personal communication).
19. Documentation of corrective actions taken by the MCO with respect to these persistent system-level problems (MacTaggart, personal communication).

VII. WHAT ORGANIZATION/STRUCTURAL FACTORS APPEAR CRITICAL TO EFFECTIVE AND EFFICIENT CARE COORDINATION?

Many authors suggest that it is not enough for a particular set of processes or activities to be implemented consistently. They note that *how* they are implemented makes a difference, and that the consistence and appropriateness of implementation will also be affected by certain, relatively intangible factors, which relate largely to the attitudes and beliefs of providers and MCOs (Saltz 1996; McManus 1997; Curtis 1999; Regenstein 2000; Schneider 2000). Although we frankly quail at the thought of attempting to measure such factors, except through reports from patients, providers and family members, we believe our conceptual framework would be incomplete without identifying them:

1. Leadership by the state Medicaid agency in convening stakeholders to identify the goals and scope of care coordination efforts.
2. Shared recognition (by state Medicaid agency, MCOs, providers, patients and families) of goals and potential benefits of care coordination.
3. Recognition by providers, and by the MCO, of the impact of the life and community context of patients on their goals, preferences, health and functioning.
4. Ongoing and meaningful communication between patients/families and providers, and across providers caring for the same patient or group of patients.
5. Trusting relationships between patients/families and providers, among providers, and between those identified as responsible for care coordination and both patients and providers.
6. Willingness of health care system actors to work collaboratively with professionals and agencies from other sectors, and vice versa.

VIII. WHAT STRUCTURES ARE NECESSARY TO SUPPORT THE CONSISTENT AND HIGH QUALITY IMPLEMENTATION OF CARE COORDINATION PROCESSES AND TO ACHIEVE INTERMEDIATE OUTCOMES?

On a more practical level, there are also specific structures and resources that appear necessary (if not sufficient) to support effective care coordination. The literature and our conversations with experts (Coleman 1979; Devers 1995; Master 1996; Saltz 1996; Watson 1997; Fox 1998; Curtis 1999; Gill 1999; Schneider 2000; Clayton, personal communication) include extensive discussions of the following elements:

1. Existence of a strategy to identify persons with disabilities (and desire) in need of care coordination.
2. Specification of the scope and objectives of care coordination in contracts between state Medicaid agencies and MCOs.
3. Specification, in states which carve out critical clinical services such as behavioral health, of mechanisms to achieve and ensure coordination between carved out services and those covered in Medicaid managed care contracts.
4. Adequate funding of care coordination activities, by the state Medicaid agency and by the MCO (as reflected in staffing levels and caseloads and other investments).
5. Use of financing tools such as risk adjustment to provide incentives for MCOs and providers to devote resources to care coordination and to care delivery for people with disabilities.
6. Specification, by the MCO, of the assignment of care coordination roles to its central staff and to clinical and other staff of its contracted providers and of the reporting and informing relationships between primary care coordinators and others. For instance, who is responsible for transferring information and how soon should it be available.
7. Structural placement of care coordination functions in a unit whose primary goal is NOT cost containment or utilization management.

8. Systems in place to ensure the timely flow of information between and among all providers (including care coordinators) caring for a particular patient, with appropriate privacy protections in place.
9. Availability of “24/7” emergency/crisis support from specially trained clinicians or care coordinators for people with disabilities identified as in need of care coordination.
10. Provision of specialized education and training to providers and MCO staff with respect to the special (and non-special) needs of people with disabilities, and the goals and operations involved in care coordination for this population.
11. Creation of teams, education of consumers, care conferences and other methods for enhancing information flow and “mutual adjustment” of providers and patients/families.
12. Current and complete knowledge, by the state Medicaid agency and the MCO, of resources at the state and local level that are relevant to the needs of persons with disabilities.
13. Development of memoranda of agreement/understanding between the state Medicaid agency and relevant state and local public sector agencies regarding coordination of services for people with disabilities.
14. Development of memoranda of agreement/understanding between MCOs and relevant local and state agencies to support coordination of medical and non-medical services for people with disabilities.

IX. CONCLUSIONS AND NEXT STEPS

This conceptual framework was prepared in collaboration with our TEP, our TAG, and staff at ASPE and the CHCS. Its development has forced us, as researchers, to think and rethink again what we and others mean when they use the term care coordination.

The conceptual framework will be used as a template to develop measures of care coordination. Specifically, we will review all existing measures for items which correspond to the long-term outcomes, short-term outcomes, and processes and structures which we have identified as being important to care coordination. Where such measures do not exist, we will develop them or revise them from other instruments. Draft measures will be reviewed by the TEP, the AG, and ASPE and CHCS. When we have a revised and final set of measures, we will test the feasibility of their use by conducting interviews with appropriate state and MCO staff.

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