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Representing community providers of services and supports for children and adults with intellectual / developmental disabilities, mental illness and other disabilities.

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Julie Hamos
Director
Illinois Department of Healthcare and Family Services
201 South Grand Avenue East
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Springfield, IL

Dear Director Hamos;

Thank you for the opportunity to provide comment on the Department of Healthcare and Family Services' Coordinated Care Key Policy Issues. Recognizing that 2013 is right around the corner, I commend the Department for beginning the discussion with stakeholders early in the process. As an association we have been avidly aware of the desire to realize better health outcomes and use resources to their best advantage for some time now. Our most recent effort was the appointment of a Coordinated Care Work Group to advise the IARF Board of Directors on how its members can be actively involved in helping the state to realize the uniqueness of coordinating the care for the population we support.

In October of 2010 IARF presented a three-day track on emerging issues that focused on health care reform initiatives and managed care. In March we were selected as one of 16 states to assess the readiness of its members for healthcare reform and to develop a change plan that will assist members in moving to the arena of health homes, medical homes and other models of integration of care. As that plan is finalized we will present a series of webcasts that explore the topics on basic, intermediate and advanced levels and provide listeners with the tools to prepare their organization and determine their place in assisting individuals achieve the best health and personal goal outcomes possible.

I believe that upon inspection, the state will find that many of its intended pursuits are already in place in community organizations and that pathways to successful linkages with physicians and other specialists exist in communities around the state despite the obstacles (i.e. availability of hospitals and physicians) that are emerging in recent discussions of integrating care and/or care coordination. This perspective should prove useful to DHFS and others in developing and readying the state for compliance with P.A. 96-1501 in 2013 and full implementation of healthcare reform in 2014.

I note with interest that you intend to hold hearings on items of the key policy document where there is no consensus. I strongly advise you to consider hearings on key policy issues relative to care coordination for persons diagnosed with mental illness and persons who have intellectual/ developmental disabilities.

In these and similar discussions, the unique needs of these segments of the general populations are ignored or glossed over. In that same area, it would be helpful for us to review information I am sure your staff has collected and analyzed about managed care efforts in other states for this population and where there are lessons to be learned from that experience. I imagine that such a review is what has guided you to this point in the development of the policy issues.

I have discussed in greater detail an area of the key policy document where our membership has reached consensus and is pursuing with great attention – that is the proposition that community organizations will be the care coordinators for individuals with intellectual/developmental disabilities and persons with mental illness.

We expect in reaching out to providers of community disability and behavioral health services that DHFS can take advantage of what is working in communities for persons with serious and persistent mental illness and those with intellectual/developmental disabilities. We are confident in our members' ability to assist the state's efforts and our intention is to show you through involvement in actions such as the policy document we have reviewed here that our members are integral to the success of coordinating care.

Beyond this submission, IARF is eager to work with the Department to meet our concurrent goals of quality care and outcomes for those we support and we look forward to the additional information we are seeking to accomplish that.

Sincerely,

Janet S. Stover

Janet S. Stover
President/CEO

How comprehensive must coordinated care be?
The obvious goal of care coordination is to ensure that resources are used to the most efficient extent possible. The experience of providers of behavioral health and disability services shows that they have been coordinating the care for persons with mental illness and I/DD. We know this population best and can provide great insight to the process and overcoming the challenge. Further, we can be an integral part of home health neighborhoods looking to the established linkages that have been carefully nurtured to ensure this population has access to health care.

In our opinion, requiring one entity to provide all the services and supports individuals with I/DD and those suffering from mental illness is unmanageable and ill advised. It is not reasonable to expect a Primary Care Practice to understand the unique needs of a child who experiences severe emotional disturbances any more than it would be reasonable for a Psychiatric Social Worker to understand how to recognize the symptoms of appendicitis. For persons with I/DD and those with serious and persistent mental illness the State must approach care coordination closest to the individual.

The Medical Home model may be a good fit for persons with I/DD recognizing that community providers have in most cases already wrapped the components of a home around the individuals they support. They are in the perfect position to understand where the obstacles are and often have identified unique ways to overcome them. For individuals who are mentally ill community providers have created health homes before they were coined in national healthcare legislation. These experiences are common and they link individuals with complex needs to the providers – health and otherwise – that are needed. We strongly urge the Department to look to these providers as unique and important parts of the healthcare solution you are seeking.

We have spent some time learning and understanding the certification process offered by NCQA. At this point, we feel further discussions should take place to understand what you are seeking to certify and whether this makes the most sense. If that conversation reaches agreement that NCQA is the best then it would seem reasonable to have that as an expectation. We are avidly interested in what other comparable certification(s) you have considered.

What should be appropriate measures for health care outcomes and evidence-based practices?
Clearly, finding physicians, dentists and other specialty providers to see patients with disabilities and serious and persistent mental illness is difficult. As we see it, the difficulty in measuring health care outcomes is that traditional measures such as HEDIS do not address the typical and/or atypical health concerns of those we support. For instance, it is not enough to measure whether a person with I/DD had a dental visit. The question is, did the dentist complete the three integral components of a dental exam: 1) dental x-rays of the bone and mouth structure, 2) did they do periodontal charting, and 3) did they perform a gum probe. Additionally, did they use a desensitization process for the visit or did they use general anesthesia screening – which is not the evidence based practice – to perform the routine?

Other data reports that the average person with a developmental disability is on seven medications:

- 59% are on psychiatric medications (only 1 in 3 has a psychiatric diagnosis)
- 52% are on a dermatology medication
- 48% are on laxatives (typically to manage the side effects of other medications)
- 46% are on anti-convulsants
- 30% are on ulcer medications
- 28% are on allergy medications.
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Despite repeated attempts by the Association to work with administrations and General Assemblies for additional funding to address behavioral add-ons and increases in nursing services in residential settings and despite multiple attempts to work on the lack of specialty care for these populations, nothing has changed. So, now in discussions such as this they are identified as “high users of the system” when in fact they are – for the most part – “ignored users of the system.”

As we work together to identify measures for outcomes and evidence-based practices it is very important to look at what is working first, and where there are areas that seem to be failing we must closely identify the root cause and address it from that angle. We have heard the Director say that it is not the rates that contribute to lack of access to health care for the Medicaid populations. And to some extent, we would agree – however, if it’s not the rate, then why is it so difficult to find specialty care for I/DD and MI populations?

It is valid to consider client risk adjustment to level the playing field. In our review of what other states have done and are considering doing with managed care and care coordination, the evidence seems pretty clear that specialty populations are most effectively served by entities that know their care best. That would point again to the utilization of community providers as care coordinators. “Adjustments” we presume relate to preventing a situation where health care providers are seeing the easiest patients and deferring those with severe and/or co-morbid diagnoses to “someone else.” It is a critical consideration and we are interested in what research you have done to identify such adjustments and whether they are effective.

We strongly recommend the Department look beyond the traditional HEDIS measures for health outcomes. For instance, social indices such as employment and affordable, stable housing are closely related to healthy lives and life styles. Best practices in Behavioral Health reflect first providing a stable living situation, then the provision of mental health, substance abuse and medical treatment; with supported employment being among the evidence-based practices leading to mental health recovery.

Illinois is also a participant in the National Association of Directors of State DD Agencies, “National Core Indicator Project.” It is also recommended as an outcome measure system for disability services programs. Additionally, you could review the Surgeon General’s seven evidence-based practices benefiting individuals with serious mental illness. We would be happy to sit down with you and have a separate conversation about these resources and review those that you might recommend for the population we support.

So our question is whether the Department of Healthcare and Family Services will consider outcome measures that are meaningful to the health outcomes of individuals with disabilities and those with serious and persistent mental illness? Sharing information with us about the quality outcomes measures other payers currently require would be helpful. Might HFS sponsor a webinar on such options so we can better respond to this question?

To what extent should electronic information capabilities be required?

There is no argument that electronic information is an integral component of good healthcare. The question is how fairly the Department will consider the historical disadvantage of community service providers on this front. There has been no real discussion of electronic records beyond the self-initiative of providers to design systems to understand how to better support those they serve and to survive in a fee-for-service environment. This initiative has resulted in the development of proprietary systems that could be converted and/or updated but not without considerable time and assistance of resources to get them there.

If community providers become care coordinators and/or integrators do they really need to be fully invested in electronic health records or do they need to have the capacity to receive and share quality and timely details of the patient for whom they are seeking medical/health treatment?

Incentives to invest in EHR is an interesting discussion. Because segments of the healthcare ecosystem are at various stages – hospitals and many PCPs are already on the other side of the hill while community providers are at different levels of incorporating electronic records into their operations.

For most community providers, an expectation of full use of EHR would be a non-starter in the discussion. However, they are uniquely positioned and fully accountable for accurate and detailed information about individuals for whom they are coordinating medical or other health care. That information can be shared “electronically” for sure but to expect fully incorporated electronic health records is a stretch especially given the fact that they are not currently eligible for the “substantial incentives in ARRA.” Perhaps HFS should consider offering financial assistance only to community providers (and others that are non-eligible) for electronic health record systems.

We would also ask what the Department has found in other states relative to incentivizing the use of electronic health records. Can this be shared with us so we can better answer this question?

What are the risk-based payment arrangements that should be included in care coordination?
As we have indicated above, our initial research suggests that a home health neighborhood might come closest to matching the needs of SPMI consumers to the capabilities of our members and perhaps the medical home model most closely matches the needs of I/DD populations based on our members' experience and expertise. In either case, we believe they are fully capable of coordinating care for the caseloads they support.

We are well aware that in managed care there is the expectation that the entity will assume risk in return for bonus and incentive payments when outcomes are met and/or exceeded. What we are unaware of is what examples you have of other states that have either assigned care for our populations to specialty care providers such as community providers and what risk assumptions are included in such arrangements.

How have other states crafted their risk-based systems; and what were the results of implementing these? Can this information be shared with us so we might better answer this question? Further, can you clarify whether you are speaking of risk-based payment at the macro/MCO level or at the micro/provider level? And we are interested to know what “stop loss” and “reinsurance” means in the context of community mental health and developmental disabilities services.

Generally speaking, assuming health outcome measures are realistic and objective, we believe it is reasonable to hold providers accountable for meeting them. We further would like to engage in a discussion of how incentives for meeting/exceeding those outcomes could be determined. Additionally, those discussions would have to include the other side of that coin – what disincentives (or perhaps risk) should be accepted by the care coordinator. Again, information that you have researched on this topic would be very helpful as we continue our conversations. Might HFS sponsor a webinar on such options so we can better respond to this question?

We also propose - as an alternative – a discussion of the shared savings model. Savings that accrue because of community providers effectively coordinating care could and should be reinvested with some proportionality to that provider.

What structural characteristics should be required for new models of coordinated care?
The questions in this section raise an interesting discussion. If you are willing to buy our proposal that community providers can and will be the care coordinators for the populations we support then it follows that contracting with hundreds of entities presents a challenge. Perhaps this is exactly the reason that state that have adopted managed care principles for this target population have opted to use a contract-entity – i.e. the Division of Developmental Disabilities as in Arizona. It has apparently worked well for two-plus decades so it’s tested.

It is imperative that care coordinators have a proven record of providing services to individuals that would be included in their care coordination proposal. As an association we have long advocated for a minimum set of financial and clinical/programmatic standards that must be met before a contract is executed between DHS and a provider. We are similarly concerned about methods to ensure a provider is capable to support individuals with increasingly complex needs before they are licensed and certified to do so.

We would be happy to bring together a small group of experienced providers to discuss this important issue with HFS and other appropriate parties.

Is there data to support either of these two approaches and what each yields as compared to the other which can be shared with us to provide a more informed response?

What should be the requirements for client assignment?

In every sense, individuals with SPMI and persons with I/DD have exercised choice of provider by selecting the community organization where they receive their support. In fact, with the conversion to fee-for-service, that individual is fully able to change providers if they are not happy with the support they are receiving. And it does happen that some individuals are “auto-assigned” to a provider. In those situations because of a particularly complex diagnosis a provider of specific expertise is contacted to support the person. These are not concepts we are unfamiliar with. Further, the longevity of relationships between individuals and their provider is the direct result of the unique expertise of providers to ensure they are informed of their choice regarding medical care and receive the support needed to help facilitate their involvement in their healthcare decisions.

The questions you raise about client assignment and network coverage decisions bring us back to our earlier point - what are the underlying reasons that medical/specialty care for persons with I/DD and those with serious and persistent mental illness is so difficult to access? Until we sit and have a serious discussion of our experience and addressing the obstacles it seems premature to determine if care coordination entities can stratify choice areas by geography or can they limit the eligible population they serve. If you think about those questions and related ones of how to incent entities to serve difficult populations, you can see that you have an effective cadre of organizations in community providers that are currently serving these populations with no exclusions.

Your specific question of methods to coordinate care for the dually eligible (Medicaid and Medicare) is not clear to me. Most if not all Medicaid waiver service providers do that now. Is there some instance that you have that could provide more detail for our consideration? Otherwise, it is unclear why this should present a problem.

How should consumer rights and continuity of care be protected?

It would seem that experience with "health care" of all shapes and sizes has proffered a set of consumer rights that would similarly be guaranteed with care coordination models. So, in the Association’s opinion, consumer rights are consumer rights. It is difficult to comment on the questions you raise because continuity of care is integral to the behavioral and developmental models of services and supports. So wouldn't that be a basic consideration of any entity that is selected?

Because, as mentioned above, there is close and common relationship built between those who are supported by community organizations and those organizations it is outside our imagination to think of providers coming and going and trying to determine a way to hand off a caseload when that happens.

It speaks to the strong reasons that care required by I/DD and MI populations can and should be coordinated by community providers who are the stable and most involved in their care.

Perhaps with additional information we could provide further comment on this section.

What is your organization's preliminary anticipation of how it might participate in coordinated care?
We have consensus among our membership that care coordination can and should be provided by these organizations who know the individual best and have been coordinating the care long before it was the “in” thing to do. Our comments are submitted on behalf of our membership and we are fully prepared to engage with the Department to work towards that end.